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Certification

Acknowledgements

AN EXAMINATION OF THE ROLE OF COGNITIONS IN THE MAINTENANCE OF DEPRESSION IN CHRONIC FATIGUE SYNDROME

by

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ATTACHMENTS

- Attachment 1: Material for GPs
- Attachment 2: Counselling Approaches Found Useful

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CERTIFICATION

I certify that the substance of this thesis is my own work and has not already been submitted for any degree, and is not currently being submitted for any other degree.

I certify that any help received in preparing this thesis, and all sources, have been acknowledged in this thesis.

Juanita Kolaric

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ABSTRACT

This study investigated the role of cognitions in maintaining a depression cycle in Chronic Fatigue Syndrome (CFS). Specifically it was hypothesised that CFS subjects would have high levels of pre-illness achievement, high levels of depressogenic thinking, particularly in the area of performance evaluation, and high levels of perfectionism. A sample of 37 CFS sufferers, a clinical control group of 27 depressed subjects and a healthy control group of 32 were drawn from general medical practices in a primary care context. Subjects were administered a questionnaire which covered demographic details; illness details - symptomatology, length of illness, stage of illness, illness attribution, criticism and support during the illness, functional impairment, psychopathology using the Hospital Anxiety and Depression Scale; pre-illness 'driven behaviour'; attitudes and beliefs - about the illness, and in depressogenic thinking - measured on the Dysfunctional Attitudes Scale, and on scales of the Multidimensional Perfectionism Scale (MPS); and preferred counselling approaches.

Conservatively, 57% of the CFS sample had a clinical level of depression or anxiety, predominantly the latter. However, CFS subjects and depressed subjects could be accurately classified on the basis of illness attribution - most CFS subjects having an external or physical attribution; most depressed subjects having an internal or psychological attribution. In a model omitting illness attribution, CFS symptoms, depression symptoms and anxiety scores provided an accurate classification of the CFS subjects, and to a lesser extent, the depressed subjects.

Some support was found for the hypothesis that CFS patients were high achievers - they had higher levels of education than their peers and had significantly higher pre-illness 'hard-driven' scores. The level of depressogenic thinking was comparable to the levels manifest in the depressed control and significantly greater than the healthy group; this effect was most marked in the construct 'performance evaluation'. Similarly, levels of perfectionism were high, comparable to the depressed group and significantly higher than the healthy group; those related to psychopathology were most marked. There was a weak trend associating an internal illness attribution to levels of psychopathology and depressogenic thinking. Illness beliefs that saw activity as damaging and a need to be seen to cope was prevalent in the CFS group, but only the latter belief was also shared by the depressed subjects.

It is proposed on the basis of the results that the challenging of unrelenting performance standards should be an integral component of any cognitive-behavioural treatment protocol. This is in addition to the previously proposed components of encouraging gentle activity, goal setting and challenging of illness beliefs relating to 'being seen to cope' and perceptions of the role of activity in the illness.

1. INTRODUCTION

1.1 GENERAL BACKGROUND

The precise aetiology of the chronic fatigue syndrome (CFS) has intrigued and mystified clinicians and researchers for the past century; during the past decade, contentions regarding the pathogenesis of the illness has developed into a considerable controversy in the medical profession and the general media (Maclean *et al* 1994). According to Wessely, discussion of the underlying cause of this illness continues to inspire “futile ‘organic versus psychological’ polemics” (1991, p 669). The one ‘fact’, however, which must not be lost sight of is that CFS is a very real, debilitating and distressing condition:

“Its hard for me to tell you how bad this has been. I wake up in the morning and feel terrible but get worse. I might have two to three good hours in the morning then I would have to rest all afternoon. I never went out at night. Talking with friends wore me out. There were some days when I couldn’t even get my body to move. The first few times that happened I didn’t have a diagnosis and I was really terrified. Terror and fear made everything even worse.”

“My life has become grey, like there is an obstruction to my perception. I am losing great chunks of my life, and my children’s.” (patients extracts from Woodward, 1993).

“I have suffered much pain, an all-consuming depression, total exhaustion to the point where I can’t walk or feed myself, frequent nausea and headaches and at times a complete inability to use my intellect.” (Leisk 1996, p 28)

It is the reality of the debilitating effects of the illness, and the general lack of treatment options that has generated the interest for the current research.

1.1.1 THE NAME

Chronic Fatigue Syndrome is predominantly characterised by the recent onset of debilitating fatigue in the absence of any explanatory medical condition. The title Chronic Fatigue Syndrome was accepted for this puzzling syndrome by the Centers for Disease Control (CDC) in 1988 (Holmes *et al* 1988). Recent names, which have presupposed the aetiology of this syndrome have included *myalgic encephalomyelitis* (ME) and *post viral fatigue syndrome* (Lloyd *et al* 1988; Loblay 1995).

An illness with similar symptoms to CFS was first termed *neurasthenia* by Beard in 1869 (Loblay 1995; Demitrack and Greden 1991). Since then, a myriad of other names and illnesses have been implicated - *chronic Epstein-Barr virus* (or *chronic mononucleosis syndrome*; or in lay terms, *chronic glandular fever*); *chronic Lyme disease*; *abortive poliomyelitis*; *neuritis vegetativa*; *neuromyasthenia*; and *Royal Free Disease* (named after an outbreak at a hospital) (Rikard-Bell and Waters 1992; Lloyd *et al* 1988; Abbey *et al* 1991; Jenkins 1991; Loblay 1995).

It has been suggested that myalgic encephalomyelitis (ME) is the most inappropriate name as myalgia is not universal among patients and there is usually no evidence of encephalitis or myelitis¹ (Lloyd *et al* 1988).

The multi-discipline interest in the Syndrome is manifest not just by the array of names that the illness has received, but also by the wide range of professions at conferences. Typically there is representation from - biochemistry, virology, psychology, neurology, psychiatry, muscle physiology, general practice, immunopathology, and magnetic resonance imaging (Dawson 1990; Loblay 1995).

¹ Myalgia - muscular rheumatism; encephalitis - inflammation of the brain; myelitis - inflammation of the spinal chord.

1.1.2 SYMPTOMS

Complaints of fatigue are extremely common in the general community - about 20% of people in developed countries complain of fatigue, and fatigue is possibly the most common symptom that brings individuals to their primary care doctor (Lewis and Wessely 1992; Pawlikowska *et al* 1994). However, while fatigue is central to a diagnosis of CFS, the criteria are prescriptive regarding the duration of fatigue - fatigue must have been present for a minimum of six months. In addition, a range of other criteria must be met.

Until 1988 when the Center for Disease Control (CDC) published a working definition of CFS, clinical and research diagnoses of the syndrome varied greatly and accordingly did resultant study findings (Holmes *et al* 1988; Schuederberg *et al* 1992). At about the same time as the development of the CDC criteria, a similar process was undertaken in the UK to reach a consensus on case definition (Sharpe *et al* 1991) and Lloyd and colleagues in Australia developed their own criteria which they then applied in an epidemiological study (1990).

The critical difference between the two sets, which has led to dissent at international scientific meetings convened to discuss the issue and further refining of the criteria, has been the emphasis placed on psychiatric status. The Holmes (1988) criteria preclude the diagnosis of CFS if the patient has chronic psychiatric illness, either newly diagnosed or previously diagnosed, and provide examples of exclusion such as endogenous depression, hysterical personality disorder, anxiety neurosis and chronic use of antidepressants. Lloyd's (1988) criteria do not incorporate any such exclusion. The Australian team - Lloyd and co-workers, have argued that the exclusion should be limited to medical conditions only, as a psychiatric exclusion, they argue, denies the prevalence of psychiatric morbidity in chronic medical conditions (Lloyd *et al* 1990).

Due to differences between these criteria and even application within each set (Schluederberg *et al* 1992), a new set of criteria was developed by the International Chronic Fatigue Syndrome Study Group in 1994 (Fukuda *et al* 1994). These criteria purport to provide a more systematic and comprehensive approach toward data collection. Interestingly, the exclusion on the basis of a past or current psychiatric diagnosis remains.

The full range of symptoms that have been identified in the Syndrome include: persistent or relapsing fatigue, fatigue after exertion, mild fever, sore throat, painful lymph nodes, muscle pain, generalised headaches, arthralgia, myalgia, paraesthesia (numbness or tingling of the skin), tinnitus (noises in the ears), photophobia, forgetfulness, irritability, confusion, difficulty thinking, inability to concentrate, sleep disturbance and depression.

A number of fatigue measures have been developed, to try to tap the precise phenomenology of fatigue in CFS (Ray *et al* 1991; Ray *et al* 1992; Chalder *et al* 1993; Schwartz *et al* 1993).

1.1.3 PREVALENCE

Reliable epidemiological data are only now becoming available, following the broad (if not detailed) agreement of the CDC international criteria in 1988. Earlier studies report figures of between 3 and 1400 cases per 100,000 (Rikard-Bell *et al* 1992)! These discrepancies can be explained by the impact of variable criteria, particularly relating to the length and severity of fatigue symptoms.

Pawlikowska and colleagues in an English study (1994) found that some 18% of general practice patients reported substantial fatigue, lasting six months or longer, although that criterion is insufficient for a diagnosis of CFS. In the same study, they identified a level of *self report* of CFS as 38 cases in a sample of 15,283 (0.25%; or 249 per 100,000).

By contrast, Lloyd and colleagues reported 42 cases in a rural/coastal Australian sample of 114,000 (0.04%; or 37.1 cases per 100,000). The former finding of self-reported CFS is almost seven times the incidence found in medically diagnosed general practice patients. Lloyd *et al* describe their finding as a "conservative estimate", based on quite stringent criteria (Lloyd *et al* 1990, p 522). It should be noted that their criteria, although similar, were not identical to the CDC criteria.

The sex ratio for patients with CFS similarly ranges between studies, notably because of the criteria applied. It is clear, however, that there are more females than males - typically samples are of the order of 65% female (Sharpe *et al* 1992).

Age of onset is usually in the late twenties, or thirties, but many adolescent cases have also been identified (Rikard-Bell *et al* 1992).

Findings have been mixed regarding the socio-economic status of patients with CFS - Lloyd *et al* (1990) found that the sample of CFS sufferers was representative of the population studied, while others have described patients as generally well educated. The latter, at least perception, has perhaps led to the pejorative term 'yuppie flu'. Woodward, 1993 states that "individuals who have developed this illness have characteristics in common. They have been active, productive and conscientious people" (p.2).

1.1.4 COURSE OF THE ILLNESS

The course of CFS varies from a minimum of six months to many years (a subject in Woodward's study talked of a 19 year history of the illness); and many have symptoms for several years prior to diagnosis (Shaffran 1991). Lloyd's and co-workers 1990 prevalence study found a median duration of symptoms at the time of study of 30 months.

The illness is not progressive and typically symptoms are most severe in the first year. Sharpe and co-workers in a 1992 study of *chronic fatigue* that specified a minimum of six weeks duration of fatigue (i.e. not CFS) found diminishing levels of functional impairment over time (73% at six to 26 weeks; 33% at two to four years). However, in CFS, relapses are frequently noted in clinical accounts (Calabrese *et al* 1992). Bonner (1994) and others refer to an extremely gloomy natural history for those afflicted. Many sufferers are unable to continue in employment or are unable to maintain previous levels of home and family functioning (Woodward, 1993). "Some of the cases seen do not improve, give up their work, and become permanent invalids" (Behan and Behan 1988).

It is important to note that most CFS research has studied patients in a tertiary referral context, and therefore it could be expected that the more severe and chronic cases have been reviewed. The course of illness in general practice may have a more positive outcome.

1.1.5 AETIOLOGY

Research into CFS is reported in the general medical, hospital, neurological, immunological, psychiatric, infectious diseases, psychosomatic and epidemiological literature. Given the elusive and heterogeneous nature of CFS, it is not altogether surprising that so many disciplines are vying for a primary place in the aetiology stakes.

CFS, Infection and the Immune System

The 'flu-like' onset of symptoms of CFS has led to a large body of research into the role of infection and CFS. Possible connections of the syndrome with the polio virus, Epstein-Barr virus (glandular fever), the Cocksackie virus and enteroviruses have all been examined, and while it would appear that many individuals with CFS have succumbed to these infections, no one viral infection

can account for all individuals with CFS, or indeed, do all those with CFS have a history of an onset related viral infection (Mowbray 1991; Lloyd *et al* 1990) The role of infection as at least a trigger or associative factor in CFS is suggested by the data.

Research, although of mixed methodological quality and findings, suggests the role of non-specific dysregulation of the immune system in a minority of CFS diagnosed cases (Lloyd *et al* 1989; Lloyd *et al* 1990; Lloyd *et al* 1993; Wessely 1991, McDonald *et al* 1991). The impact of stress, adversity and depression on the immune system is well established (Chase 1991). It has been suggested that the minor immunological deficiencies found in some CFS patients may be attributable in part to co-existing depression (Shafran 1991).

CFS and Neuromuscular Disorder

One of the central features of CFS has been the increase in fatigue and myalgia reported by patients following exercise. This has led to detailed studies of muscle function (Gibson *et al* 1993; Lloyd 1990).

Gibson and co-workers (1993) conducted a study in which they compared the exercise performance and fatiguability of CFS patients with a sedentary group². They concluded that the contractile properties of the muscles and the recovery of muscle function were normal in the CFS group and that patients did not show excess fatiguability. However, the CFS group did not exercise to their physiological capacity and had a greater perception of effort. They suggested that the findings “should give confidence to patients that graduated exercise can be safely undertaken without risk of damage to their muscles” (p 998).

Riley and colleagues (1990) found a decreased capacity for aerobic exercise in their CFS sample, compared to their two controls - subjects with irritable bowel syndrome and ‘normal’ subjects; the decreased capacity was consistent with

deconditioned subjects. No 'sinister' abnormalities were found. Similar to the Gibson study, the CFS subjects had a greater perception of effort than the other groups.

In short, consistent evidence of muscle or neuromuscular dysfunction has not been found.

1.1.5.1 CFS and Neurology

Patients with CFS usually have normal neurological examination results although more sophisticated techniques for examining brain structure, metabolism and blood flow are only just beginning (Lloyd 1990).

Several studies have been conducted to look at memory, concentration, motor function and sleep disturbance in CFS patients. In summary, the results have identified that patients report high levels of cognitive and memory dysfunction (Smith *et al*, 1993), although when actually tested, memory impairment is found to be mild (Grafman *et al* 1993; Scheffers *et al* 1992).

In a small sample, perceptual, attentional and short term memory processes as measured by event-related brain potentials were unaffected in CFS patients, but reaction times were more variable and slower than in the control).

In a study involving a multiple sclerosis and a healthy control group, some CFS patients had significant elevations in sleep disturbance which the authors concluded were potentially treatable sleep abnormalities (Krupp *et al* 1993).

Again, neurological processes have been found to be implicated in CFS, but studies have not suggested an aetiological role or focal area of dysfunction.

² This was not defined in the study, however, it was stated that none of the control group took regular exercise. Presumably, they were matched 'normal' subjects who did not exercise.

1.1.5.2 CFS and Nutrition

Environmental factors and diet are purported by alternative health therapists as being causal in developing CFS symptoms (French 1993). Accordingly, diets to reduce candida levels or to remove harmful body toxins are regularly advocated.

There have been few if any systematic studies of the nutritional status of patients with CFS (Stewart 1991). However, it is apparent that those with CFS have availed themselves of nutritional supplements and modified their diets in an attempt to improve their lot. For example, Woodward's 1993 study found that 78% of her 50 subjects took vitamin supplements.

1.1.5.3 CFS and Psychiatry

It would appear that psychological distress and psychopathology, particularly depression and anxiety disorders, play at least an interactive role in the chronicity of CFS. As these factors are central to the current research they are dealt with more fully below in a broader outline of psychological factors in CFS.

In summary, the aetiology of CFS appears mixed as is the case in many medical and psychiatric illnesses. Wessely and Powell concluded in their 1989 study that as 28% of their sample had no psychiatric disorder, depression cannot be the sole explanation for the symptoms of CFS; similarly, a large minority of those with CFS have no history or evidence of a precipitating viral illness (and less so of a unitary virus). Similarly it has also been found that immune dysfunction only occurs in a minority of cases. It would appear that an integrative approach regarding the aetiology of CFS should be employed in explaining the findings.

Again, it should be emphasised that regardless of the precise aetiology of CFS, the illness causes great emotional, cognitive and social distress and dysfunction in the majority of sufferers. Despite the multiplicity of possible causal factors, a search for effective treatments is paramount.

1.1.6 TREATMENT - Wait for the 'Magic Bullet', Rest and 'Live Within Limits'

The 'best' treatment on offer to patients assessed for CFS consists of "establishing the absence of treatable disease [!]; acknowledging the reality of the patient's illness; diagnosing "post infectious" or "idiopathic" fatigue; and optimistic reassurance about prognosis." (Sharpe *et al* 1992, p 148). In short, typically no treatment is offered. Patients are left to languish, perhaps with the faint hope that the particular pathogen causing the distressing illness will be found, rapidly followed by a medically based cure. Self help groups and often the medical profession advocate rest until symptoms remit; this sometimes takes years if it occurs at all (Wickham 1996).

Some patients adopt a more proactive role by participating in immune deficiency treatment trials, which in controlled studies have proven to be no more effective than placebo effect (Hauben 1993). These studies have involved a range of treatment substances (Wilson *et al* 1994; Shaffran 1991; Lloyd *et al* 1993; Rotheram 1991; Hauben 1993; Midland 1994).

Others have modified their diets, used the cold bath treatment (ME/CFS Society (SA) Inc 1994; Bridgewater 1995) or modified their lifestyles to engender a healthier, more resistant immune system, and yet others have tried extensive exercise programs with mixed results (Woodward 1993; French 1993; Doepel 1993; Lloyd 1990).

Surprisingly, the possible therapeutic benefits of anti-depressants have not been trialed (Sharpe 1992). At present the range of views on their benefits vary dramatically from doctor to doctor and between the disciplines. Other psychologically based treatment approaches have been proposed and tested in two studies which are discussed more fully below. In short, however, psychological treatment approaches have not been considered a mainstay.

In summary, at this stage very limited medical and psychological treatment options have been offered to patients with CFS; not surprisingly (and with some benefit) most sufferers have attempted to gain succour from the 'alternative' nutrition and lifestyle based treatments.

1.1.7 FACTORS ASSOCIATED WITH THE PROGNOSIS OF CFS

There are few long term investigations of prognosis (Shaffran 1991). Wilson and co-workers in a longitudinal study (1994) of global outcome, psychiatric 'caseness', and immunological functioning found that immunological functioning did not predict outcome (nor did participating in a trial of immunological treatment); premorbid psychiatric diagnoses did not predict outcome; and that *the only two factors that predicted outcome were psychiatric 'caseness' at the time of follow up, and strength of belief that a physical disease process explained all symptoms at entry to the trials. Both were associated with poor outcome.*

The authors concluded that "psychological factors were important determinants of outcome, even though alternative predictor variables (age at onset, duration of illness and immunological function) were entered before measures of psychological function in the analyses." (p 758-759). They went on to suggest that subjects who dealt with distress by somatisation and who discounted psychosocial moderating factors in their illness are more likely to have a poorer prognosis.

Sharpe and others (1992) found that duration of symptoms, or demographic factors did not relate to later functional impairment, but beliefs, coping behaviours and social factors were significant. *Specifically, they found that belief in a viral cause of the illness; coping by limiting exercise and avoiding alcohol; changing or leaving a job or studies, and joining a patient organisation were predictive of poorer outcome.* Consistent with the Wilson study, they also found that

emotional disorder at the time of follow up was associated with functional impairment.

Butler and Bonner and colleagues in their 1991 study and 1994 follow up of the efficacy of their treatment trials found that *outcome depended more on the strength of initial attribution of symptoms to an exclusively physical illness (ie a strong conviction predicted a negative outcome) than on the duration of illness*. In the follow up study this finding was maintained, but *they also found that patients that did not improve tended to have more somatic disorders, to be more fatigued and, contrary to the Wilson study, to have had a psychiatric history*.

In summary, demographic factors, duration of illness, and immunological functioning are not indicative of prognosis. However, belief in a physical cause of the illness, and coping strategies which involve avoidance of activity are adversely associated with outcome. Psychiatric status, at least during the course of the illness (there is some inconsistency regarding the predictive value of psychiatric status at onset) also appears to negatively predict outcome. The findings regarding psychological factors such as attitudes, beliefs and ways of coping suggest avenues for potential treatment to ameliorate the long term effects of this chronic illness.

1.2 PSYCHOLOGICAL FACTORS IN CFS

In addition to the above studies which consider attribution of illness to a physical cause, there have been other studies which have examined a range of psychological factors hypothesised to be of importance in the illness. Many studies and reviews have canvassed the prevalence and role of psychological distress/ psychiatric 'caseness'; some have looked at the issue of coping styles and behaviours; others at issues of self esteem; and others have explored ways of thinking and behaving which have included attitudes to the illness itself.

1.2.1 EMOTIONAL DISTRESS/ PSYCHIATRIC STATUS

It is in considering the psychological wellness of patients with CFS that the lid is lifted from the Pandora’s box.

1.2.1.1 Overlap of Symptoms

Firstly, the similarity and overlap in symptoms between CFS and the symptoms of primary psychiatric diagnoses, particularly depression are manifest. Noticably, the somatic manifestations of depression overlap considerably with the symptoms of CFS - fatigue, psychomotor retardation, diminished ability to think or concentrate, sleep disturbance; further, a diagnosis of CFS may also incorporate the remainder of the criteria for depression (WHO - ICD-10 1992; DSM IV 1994).

Table 1Diagnostic Criteria for CFS and Depression

CFS (Fukuda et al 1994)	Depression (WHO 1992)
<u>Key criteria</u>	
Fatigue	Reduced energy leading to increased fatigability and diminished activity Depressed mood Loss of interest and enjoyment
<u>Additional criteria</u>	
Post-exercise fatigue	Marked tiredness after slight effort
Short term memory impairment	Reduced concentration and attention
Unrefreshing sleep	Disturbed sleep
Sore throat	Reduced self-esteem and confidence
Tender cervical or axillary lymph nodes	Ideas of guilt and unworthiness
Muscle or joint pain	Bleak and pessimistic view of the future
Headaches	Suicidal ideation

An article prepared by a general practitioner for the ME/CFS Society in Canberra points up the confusion regarding the overlap in many of the symptoms of depression and CFS. The article (ACT Division of General Practice, 1995)

summarises the symptoms of depression; indicates that fatigue and depression are features of many physical and psychiatric illnesses; and then suggests that where an individual with CFS has depression it is a reasonable reaction to the losses associated with the illness.

Jenkins (1991) comprehensively lists the psychological and physical symptoms of 'ME' and from her own experience with patients, contrasts the former with comparable symptoms listed in depression. Her approach, in contrast with the above mentioned article, is not to suggest that depression may be a part of CFS, but rather that where the symptoms occur, there are qualitative differences associated with the two illnesses. She states that while in depression mood is consistently low, in CFS, where it is low it is more labile; in CFS depression is associated with frustration with being unable to pursue normal activities rather than being associated with a lack of interest in usual activities as is found in depression; fatigue in depression, she purports is related to a lack of motivation, whereas in CFS it is associated with being unable to exercise; in depression, impairment in concentration is associated with the severity of the depression, whereas in CFS, concentration is associated with severity of fatigue and suggests that specific cognitive abnormalities are present (memory problems, finding words, clumsiness).

Some of these purported qualitative differences in the reported symptoms of CFS patients and those with depression have been followed up in studies, and some have been summarised above in a discussion of neurological differences.

However, there is much scope for further study of the underlying differences between the symptoms of CFS and other medical and psychiatric disorders where fatigue is a central element.

In focusing on the overlap of symptoms between CFS and depression, Abbey and colleagues (1991) caused great controversy when they presented an article in which they argued that CFS was a "culturally sanctioned form of illness behaviour" (p 1638) and predicted that it would receive the same decline in social value once it was demonstrated that most sufferers were experiencing primary

psychiatric disorders. They ruled as has Wessely (1991) that the preference of a 'medical' or organic diagnosis points to the continued stigma attached to psychiatric illness and psychological distress.

1.2.1.2 Psychiatric 'Caseness'

The incidence of psychiatric 'caseness' found amongst study subjects is universally high. All studies that have examined the co-morbidity of CFS and psychiatric disorders have found a very high incidence, primarily of depression, but also of anxiety and somatisation disorder (Wessely 1991). The findings range from a psychiatric 'caseness' of 45% (Hickie *et al* 1990) to the majority of studies which report a psychiatric diagnosis in well over two thirds of CFS patients.

In Hickie's and co-workers' study a variety of interview and questionnaire instruments were used to diagnose DSM-III-R disorders in 48 CFS patients referred to the Prince Henry Hospital in Sydney. They found evidence of major depression in 46% of the patients and an incidence of 12.5% of a major depressive episode predating the CFS. They concluded that their patients did not have a higher premorbid incidence of depression in comparison with other community-based studies. (Hickie *et al* 1990).

Shaffran (1991) reviews four studies that determined the psychiatric status of CFS patients using the National Institute of Mental Health Diagnostic Interview Schedule. They each found a significantly higher level of depression in the CFS groups than amongst their controls. Taerk and co-workers (1987) and separately Manu and others (1988) reported that 50% of their ME/CFS groups had a major depressive episode *predating* the ME/CFS. Kruesi *et al* (1989) found that 75% of their CFS sample had identifiable psychiatric diagnoses.

It should be borne in mind that the variation in prevalence of psychiatric disorders will vary depending on the particular sample being investigated - many are tertiary referred hospital samples; because of the slightly different criteria for

diagnosis of CFS that have been employed in each study; and thirdly, because different instruments have been applied - some interview and some questionnaires, to determine 'caseness'. The latter issue is canvassed more fully in the discussion of the most appropriate measure to employ in the current study.

However, notwithstanding the variation in samples, criteria and measures, there would appear to be conflicting evidence as to the premorbid rate of psychiatric illness amongst CFS patients (ranging from the community level found in Hickie's study to 50% in other studies). However, in all of the above studies, current levels of a psychiatric diagnosis was consistently high - ranging from 46% in Hickie's study to more typically between 66% and 75% in the other studies (Wood *et al* 1991).

This brings to mind an obvious question - is the co-morbid psychiatric diagnosis, usually depression, primary or is it a reaction to the illness? The premorbid prevalence of psychiatric illness would suggest that in some individuals there is a psychological predisposition factor in CFS, however, the figures are not high enough to declare a categorical aetiological link.

To further elucidate this question, and to help tease out the confounding issue of fatigue as a symptom of both CFS and depression, Wessely and Powell (1989) compared "postviral chronic fatigue patients" (who met the criteria for what is now called CFS) with two control groups - patients with fatiguing neuromuscular disorders and patients with major depression. To remove the possibly confounding factor of fatigue from psychiatric diagnoses, they excluded fatigue as a symptom of psychiatric disorder. They found that 72% of the CFS patients satisfied diagnoses of psychiatric disorder. This is consistent with the above mentioned studies. By contrast, 36% of the neuromuscular group who also experienced fatigue were given a psychiatric diagnosis. They found that the CFS patients more closely matched the affective group. Of interest also is their finding that in the CFS group and the affective group, physical fatigue was associated with mental fatigue. This was not true for the neuromuscular group except where a psychiatric illness was also present.

1.2.1.3 Prevalence of psychiatric disorders

In a similar vein, Wood and co-workers (1991) contrasted the psychiatric status of CFS patients attending a general medical clinic at a teaching hospital with patients diagnosed at the same clinic with muscle disease. Both had impairment affecting their everyday activities. Sixty seven percent of the CFS patients and 16.5% of the muscle disease patients were assessed as satisfying psychiatric diagnoses.

Krupp and colleagues (1991) in a study that compared CFS patients with other medical conditions where fatigue is a major symptom (multiple sclerosis, systemic lupus erythematosus and Lyme patients), reported that 70% of their CFS patients had DSM-III-R diagnoses. The prevalence of depression using the Center for Epidemiologic Studies Depression Scale was higher among the CFS group than among the medical controls. They concluded that because some 30% of the CFS group did not receive a psychiatric diagnosis that “CFS can not be wholly attributed to psychological factors”. (p 407).

To summarise, the relative risk of a psychiatric disorder varied with a ratio of 3.3:1 for CFS compared to patients with muscle disease (Wood *et al* 1991); or 2:1 in Wessely’s 1989 study which conservatively excluded fatigue as one of the determinants of psychiatric ‘caseness’; and 1.4:1 in comparison to patients with chronic pain (Blakely *et al* 1991).

Consideration as to whether to include or exclude patients with a psychiatric diagnosis from a diagnosis of CFS has led to the use of differing criteria for the diagnosis of CFS as has been discussed above. The Lloyd Sydney team’s criteria did not exclude patients from the diagnosis on that basis, but the CDC, and recently agreed criteria developed by the international committee have prescriptively excluded patients from the diagnosis of CFS if they have an existing or past psychiatric disorder.

1.2.1.3 Subjectivity of Symptoms

Many biological markers have been suggested for CFS and routine immunological tests are carried out prior to diagnosis, however, to date no definitive test has been identified. As Wessely points out “It does not mean that symptoms are factitious in origin, which is still an issue in the media, even though never considered by serious investigators of CFS, nor that psychiatric disorders are the cause of CFS” (1991, p 669). However, it means that the medical practitioner must consider a diagnosis on the basis of often descriptive information (Krupp *et al* 1991). This could partially explain the reluctance of general practitioners to diagnose CFS as was found in Woodward’s descriptive study of the illness and its course (1993).

1.2.1.4 Problems with Measuring Depression in Medically Ill Patients

Ray (1991) tried to tease out the ambiguities and issues associated with assessing depression in medically ill patients. She notes that in neurological disorders such as Parkinson’s disease and multiple sclerosis; and endocrine, metabolic and nutritional disorders, patients readily meet the criteria for a depressive syndrome even though the symptoms derive from a clear cut organic basis. She concludes that the presence of depressive symptoms does not point to the aetiology of an illness but may suggest that the disorder may involve processes that are in some way linked to depression.

Ray (1991) makes the obvious link that the losses and stresses of an illness itself may result in psychiatric symptomatology. “Most will severely restrict their activity, because of fatigue, and this will result in a loss of social and other rewards, and sow the seeds of disengagement and depression.” (p 3).

The prevalence of psychiatric diagnoses in CFS studies must be considered in the light of the ambiguity of somatic depressive symptoms in many medical illnesses. However, it must also be noted that even in studies where measures of depression

have been used that do not include somatic symptoms, psychiatric ‘caseness’ is still high (eg Wood *et al* 1991).

1.2.2 SOCIAL SUPPORT

Little has been done to look at the role of social support for individuals with CFS although it has been recognised as important (Blakely *et al* 1991). Ray (1992) in developing a measure of social support for use with chronically ill patients, examined the association between both positive and negative social support, and functional impairment, anxiety and depression in a sample of CFS patients. She found that while social support was not associated with functional impairment, lack of positive support was associated with anxiety; and negative support was associated with anxiety and depression. It has been found in the broader literature that social support can mitigate against depression in the ill (Revenson *et al* 1991).

A study by Lewis and colleagues (1994) included an examination of perceived levels of social support before the onset of CFS. Compared to patients with irritable bowel syndrome, and healthy controls, CFS patients reported significantly lower levels of social support. Lewis proposed that the low perceived support may have contributed to depression and to immunological changes - they drew on literature which finds associations between low levels of social support and negative impacts on neuroendocrine or immune system functioning (Jemmott and Locke 1984).

1.2.3 PERSONALITY AND COPING STYLES

Few studies have examined in any detail the phenomena of psychological factors in CFS. Most studies have used broad brush approaches which have yielded a single score and categorisation of psychiatric status.

Blakely and colleagues (1991) conducted a study which aimed to elucidate the psychological characteristics of CFS. While their objective was ambitious, they used a variety of psychometric instruments (including the Minnesota Multiphasic Personality Inventory (MMPI)) to provide more specific information on psychiatric symptoms, personality and ways of coping in the illness. They found some communality between the CFS and chronic pain groups in terms of personality traits, particularly the MMPI 'neurotic triad' (hypochondriasis, depression and hysteria); but the CFS group showed more extreme levels of 'emotionality'. They also found that CFS subjects tended to use more escape/avoidance; distancing; and accepting of responsibility as ways of coping with a recent stressful event.

Ray and colleagues (1993) conducted a study in which they explored the ways that patients coped with CFS, and they canvassed the most appropriate ways for patients to manage their illness. Such a study finds precedent in the exploration of coping in other chronic illnesses (Rosenstiel *et al* 1983; Turner *et al* 1985; Keefe *et al* 1988).

They noted the conflicting views about the benefit of exercise and rest - one study of a treatment protocol that involved exercise and activity seemed to have positive effects (Butler *et al* 1991) while others have argued that patients with chronic illness show great insight in avoiding activity and exercise (Ray *et al* 1993). The results supported four illness management factors - maintaining activity, accommodating to the illness, focusing on symptoms and information seeking. These in turn were associated with outcome in the following ways - maintaining activity acts to protect everyday functioning but at the cost of increased anxiety; accommodating to the illness safeguards emotional adjustment, but at the cost of functional impairment; focusing on symptoms (associated with helplessness) was associated with both greater functional impairment and worse emotional adjustment; and information seeking protected functioning but was not associated with anxiety or depression.

Ray and colleagues concluded that assessing an individual's way of coping in CFS may be useful information which can be utilised in psychological interventions.

1.2.4 WAYS OF THINKING AND BEHAVING

1.2.4.1 Attitudes to the Illness

1.2.4.1.1 Attribution of the Illness

As has already been outlined above, patients attributing CFS to a physical/organic cause has been found in repeated studies to be associated with poorer prognosis (Powell *et al* 1990; Butler *et al* 1991; Sharpe *et al* 1992; Bonner *et al* 1994; Wilson *et al* 1994).

Several studies have found that CFS sufferers tend to have such a physical attribution for their illness (Wood *et al* 1991; Wessely and Powell (1989).

Hickie and colleagues (1990) in their study which primarily looked at the psychiatric status of their CFS patients, also administered the Illness Behaviour Questionnaire (Pilowsky *et al* 1975) which was developed to measure dimensions of abnormal illness behaviour. They found that CFS patients had a strong conviction that they were physically ill, were reluctant to accept a psychological interpretation for their illness, and had a tendency to regard their illness as the sole problem in their lives. They also found that CFS patients did not have excessive levels of hypochondria. Schweitzer and colleagues (1994) replicated Hickie's study and found the same illness attitudes as in the earlier study. By contrast, however, they also found inflated scores on 'general hypochondriasis', which is suggestive of a phobic concern with symptoms. Interestingly, most of the IBQ scales differentiated CFS patients from their psychiatric control.

Ray and colleagues (1992) in a study that looked at CFS symptom components concluded that their data could fit either of two scenarios - CFS could represent a form of somatisation ; or alternatively it could be an organic disorder with associated emotional features (as is found in other medical conditions). They suggested that the relationship between mood and the illness symptoms may be a reciprocal one ie discomfort lowers mood and lowered mood from not achieving as much exacerbates symptoms.

Finally, a study by Powell and others (1990) further expanded the meaning and implications of CFS patients having a predominantly physical attribution for their illness. A higher perception of helplessness amongst medically ill patients has been found to be associated with increased levels of anxiety and depression (Rosenstiel and Keefe 1983; Turner and Clancy 1986; Keefe *et al* 1989).

In Powell's study, depression was assessed using the Schedule for Affective Disorder and Schizophrenia (SADS). Fatigue was excluded as a criterion because of possible confounding effects. Indices of guilt and self esteem were derived from the responses. In this sample, 80% of CFS patients attributed their illness to a physical cause, with the reverse being true for the affective control group. The illness was perceived as being potent, uncontrollable, aversive and frightening. In contrast to the depressed group, the CFS group, and more specifically the subgroup of CFS patients who were diagnosed as depressed, experienced significantly less guilt/self blame and had higher levels of self-esteem; the groups were similar in measures of affectivity and biological symptoms but differed in cognitions relating to self worth. This finding is consistent with attribution theory (Abramson, Seligman and Teasdale 1978). - the external illness attribution found predominantly in CFS patients protects their self-esteem. The authors suggest that the external attribution protects cognitive changes associated with low mood, but at the expense of greater vulnerability towards somatic symptoms such as fatigue. They concluded that cognitive therapy should be of benefit in therapy.

Wessely (1991) suggests that there is a cost involved in attributing symptoms to an external cause. The benefits are that the illness is easier to understand; it

suggests no self blame or guilt; and has no stigma attached. The disadvantages, he suggests, are that the simple explanation may be misleading; it may obscure symptoms of depression; it offers no opportunity to control symptoms (increased helplessness); offers no treatment; and is associated with a decline in self-efficacy.

An alternative explanation for the results could be along the lines suggested by Ray - the 'depressive' symptoms, particularly the somatic ones could be purely associated with the illness itself, rather than depression per se; accordingly, fewer cognitive depressive symptoms would be expected.

1.2.4.2 GENERAL WAY OF THINKING

While several other studies have examined illness attributions and some have tried to tease out the phenomenology of depression in CFS, one has examined a specific cognitive style in patients with CFS. Petrie and colleagues (1995) looked at the impact of catastrophic beliefs in CFS. The individuals (a large sample of 282) were asked about the consequences of pushing themselves beyond their present limits. Responses were dichotomised as catastrophic (i.e. beyond worst possible outcomes e.g. 'I'd probably have a stroke and die') or not. These two groups did not differ on the length of the illness or psychological adjustment. However, the catastrophisers had higher levels of fatigue; had a higher level of functional impairment (e.g. did less - paid work or work in the home); and experienced greater disability in sleep and rest, social communication and recreational activities. It could be argued that the 'catastrophisers' had good cause to have a bleaker view of the impact of over exerting themselves, but the authors point out that the symptomatology as well as duration of illness was comparable in the two groups. They conclude that changing catastrophic perceptions of increased activity may be critical to recovery and in breaking the chronic cycle of the illness. They also suggest that "treatments of CFS that emphasise the need for rest and avoidance of activity may in the end be counter-productive to recovery" (p 35).

There is a dearth of studies in the area of general cognitions in CFS sufferers.

1.2.5 POSSIBLE MAINTENANCE OF DEPRESSION IN CFS

The findings of the studies outlined above indicate that the incidence of depression is high in CFS. This can be partly attributed to the typical inclusion of somatic symptoms in such diagnoses, however, even in studies which have excluded somatic symptoms, depression is still found in many with the illness. Whether there is an aetiological role of depression in CFS, or alternatively that the depression that is often manifest results from the debilitating effects of having such a chronic illness, there does appear to be some level of depression in many people with the syndrome. While the former proposition is open to conjecture, the latter suggestion that the depression that is found is reactive in nature, is consistent with the helplessness prediction of depression alluded to above - few would argue that CFS is an aversive, seemingly uncontrollable and noxious illness to be unfortunate enough to develop.

If there is scope to assist CFS patients to avoid the additional burden of depression, then this author believes that those avenues should be actively explored. Below is a brief outline of the theories of depression and an exploration of how a model that examines thinking and behaviour has been postulated as explaining a maintaining cycle of depression in many chronic illnesses.

1.2.5.1 THEORIES OF DEPRESSION

Theories of depression derive from three main schools of thought - the biological model, the psychodynamic model and the cognitive behavioural model (Rosenhan and Seligman 1989). Under the biological model it is thought that depression arises from neurotransmission malfunctioning in the brain. Accordingly, medications and treatments designed to restore the chemical imbalance in the

brain are employed. As noted above in the discussion of treatments of CFS, it is somewhat surprising given the fairly widespread use of anti-depressants that controlled studies of their efficacy in CFS have not been conducted. Certainly *opinion* about their efficacy is divided (Jenkins and Mowbray 1991).

Psychodynamic theorists articulate three causes of depression - anger turned against the self, excessive dependence on others for self-esteem, and helplessness at achieving one's goals. Therapy, of each of these facets, involves bringing the individual to a realisation of their tendencies and to refocus their energies in a more *egosyntonic* way.

1.2.5.1.1 Cognitive and Behavioural Models of Depression

The most topical theoretical perspective on depression in the past decade has been the cognitive-behavioural model. The main theories postulated under the cognitive-behavioural banner include those that place the focus of causality on the quality of an individual's relationships with his/her environment (Lewinsohn *et al* 1985); and the cognitivists who suggest that negative and often self-deprecating ways of thinking play a central role in depression (Beck 1979; Ellis 1975; Abramson and Seligman 1978).

1.2.5.1.1.1 Integrative (behavioural) Model

Under Lewinsohn's 'integrative' theory of depression (Lewinsohn *et al* 1985) depression is said to occur when there is a decrease in pleasant events or an increase in unpleasant events. He postulates that once negative life events occur the usual patterns of behaviour stop; the individual then receives less gratification as they have ceased activities that previously gave them pleasure; if the individual then engages in self-critical and negative thinking they will experience increased dysphoria and the full spectrum of behavioural, cognitive, emotional, somatic and interpersonal depression symptoms; this experience in turn is a distressing event

and the cycle continues. Superimposed on this cycle, Lewinsohn suggests that individuals may have predisposing vulnerabilities for depression (e.g. gender - mostly females; age - 20-40; previous episode). Treatment or interception at any point in the cycle will reduce the severity of the depression.

Lewinsohn states that as well as being able to explain the full range of depressive symptoms, any theory of depression must adequately explain the central feature of depression, dysphoria. He claims and cites research to support the claim, that “dysphoria is the only depression symptom that comes close to being invariant” (1985; p 337); he later goes on to state “our assumption is that without dysphoria only a very incomplete syndrome will exist since neither the changes in processing of information about the self nor the depression-induced social behaviour changes will have occurred.” (1985, p 351) This is interesting to bear in mind in the context of the distinction being made between somatic and cognitive symptoms in CFS.

1.2.5.1.1.2 Beck's Cognitive Model

Beck's cognitive model of depression (Beck 1976) suggests that an individual's experience leads him or her to develop assumptions or schemas about the world which helps in daily interpretation of events. However, some assumptions are rigid and extreme and are described as ‘dysfunctional’ (this author usually describes them to clients as being ‘very unkind to oneself’). Once started, these dysfunctional assumptions lead to a bevy of ‘negative automatic thoughts’ (they pop into the head and are associated with negative emotions) (Fennell 1993). The thoughts are conceptualised in the model as being to do with oneself (‘I am hopeless and inadequate’); current experience (‘everything around me is terrible’); and the future (‘the future will be hopeless’).

Examples of the dysfunctional assumptions are:

1. In order to be happy, I have to be successful in whatever I undertake.

2. If I make a mistake, it means I am inept.
3. I can't live without love.
4. To be happy, I must be accepted by all people at all times.
5. If someone disagrees with me, it means he doesn't like me.
6. My value as a person depends on what others think of me. (Rosenhan and Seligman 1989)

The model can be presented as follows:

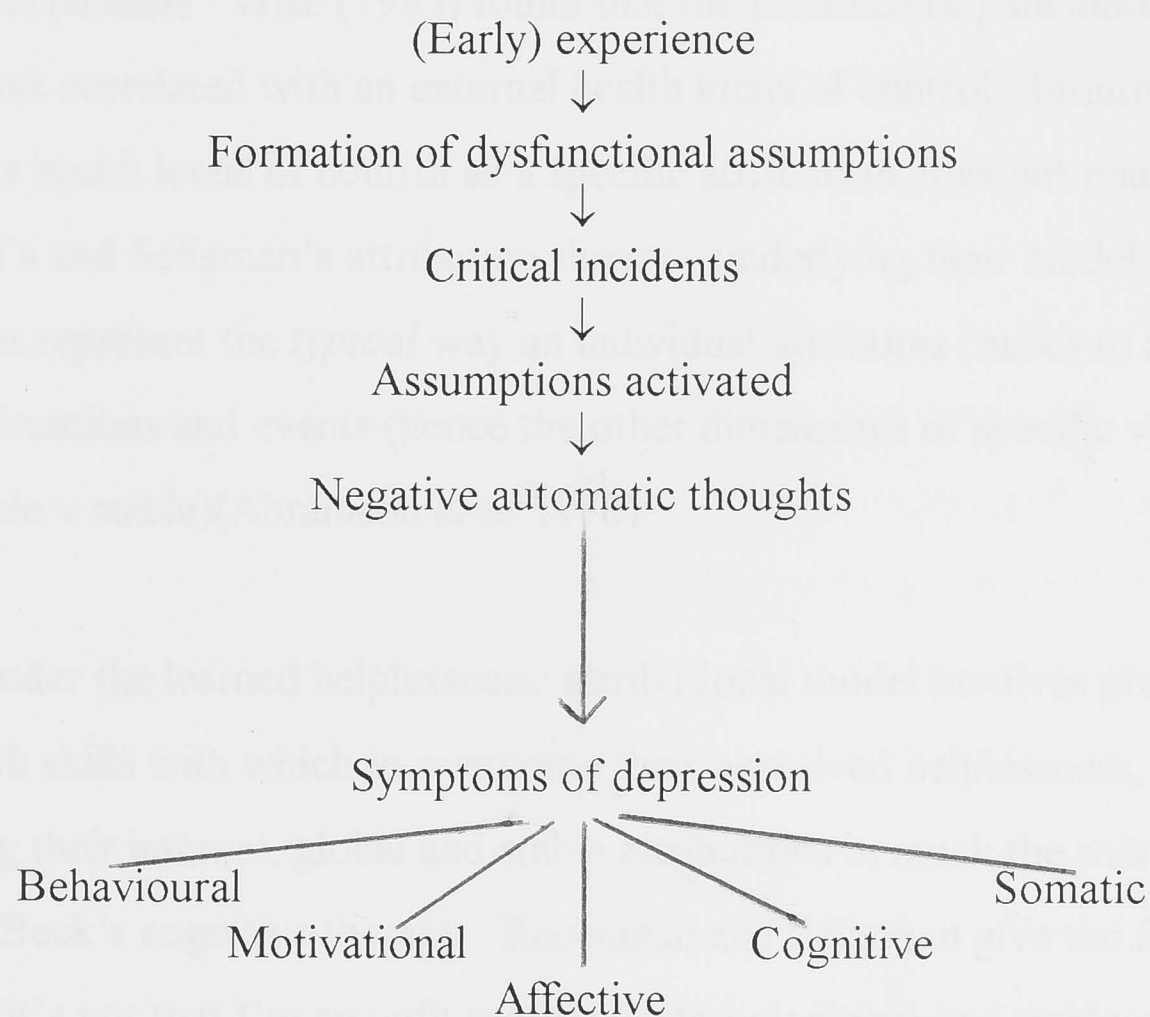


Figure 1 Beck's cognitive model of depression (from Fennell 1989, p 171)

Ellis and Harper (1975) provide a form of cognitive therapy based on similar principles - they state that individual's 'irrational beliefs' cause them to overreact emotionally to situations and to become depressed.

Seligman's theory of learned helplessness has been discussed above in the context of understanding the illness attribution of CFS patients - having an external attribution ie physical illness, to an uncontrollable and aversive event ie CFS, has been proposed in line with the theory, as providing a buffer for protecting self esteem. The study by Powell (1990) and others has provided data consistent with this hypothesis.

Lau (1982) in a seeming extension of Seligman's work, developed a specific health locus of control beliefs dimension which has been tested with depressed and anxious patients. Wise (1985) found that the presence of pain among subjects was correlated with an external health locus of control. Intuitively, however, a health locus of control as a specific attribution does not readily fit with Abramson's and Seligman's attribution theory - underlying their model, attributions represent the *typical* way an individual attributes causes to a *wide range* of situations and events (hence the other dimensions of specific v global; and unstable v stable)(Abramson *et al* 1978).

Therapy under the learned helplessness/ attributional model involves providing the patient with skills with which to overcome their perceived helplessness, as well as challenging their internal, global and stable attributions in much the same way as is done in Beck's cognitive therapy. Rosenman and Seligman give the following example: "it's not that I'm an unfit mother, [internal, global and stable attribution] rather I'm grouchy at 7 A.M. [unstable and specific]" (1989, p 344). If you also add "and so are most people at that time of day" it also becomes an external attribute and will preserve self esteem.

Cognitive behaviour therapy is described as "a complex interweaving of cognitive and behavioural techniques" (Fennell 1989, p 170). It incorporates the behavioural component of Lewinsohn's model - the scheduling of pleasant events; the challenging and modification of negative cognitions and assumptions as

proposed by Beck; and of challenging and modifying depressive attributions as in Seligman's helplessness model.

1.2.5.2 Cognitive-behavioural Therapies Applied to Chronic Illness

The role of cognitions in predicting illness outcome has been found to be significant in a variety of chronic illnesses (Levine *et al* 1987; Flor *et al* 1988; Smith *et al* 1988; Devins *et al* 1982; Greer *et al* 1979; Wessely and Lewis 1989; Maes and Schlosser 1988).

Predicated on these findings, cognitive and behavioural therapies (CBT) have been applied as a treatment in a number of illnesses leading to gains in functional improvement, often striking improvements in depressive symptoms, and often reductions in illness symptoms (Pither 1989).

Smith and colleagues (1988) examined the cognitions of patients with rheumatoid arthritis, an illness that is often accompanied by significant levels of depression and disability. They set out to test the applicability of Beck's cognitive model and found that even when disease severity was controlled for, cognitive distortions were significantly associated with both depression and physical disability.

The efficacy of cognitive and behavioural coping strategies have also been examined and found to significantly associate with illness outcomes (Turner *et al* 1986; Rosentiel *et al* 1983; Keefe *et al* 1989).

1.2.5.2.1 CBT Applied to CFS

1.2.5.2.1.1 The Research

Two CBT treatment studies have been published, each with its own limitations. One study (Lloyd *et al* 1993), while methodologically sound in terms of research

design (double-blind, placebo controlled) purported to apply CBT to patients as a comparison treatment to the immunologic agent dialyzable leukocyte. However, in this study only a limited behavioural component of CBT was applied - increased physical exercise; there was no discussion of any cognitive component in the treatment, nor any goal setting relating to re-engagement in pleasurable activities. In this study no treatment effect was found for what they described as a CBT protocol.

The second study by Butler and colleagues (1991), and its four year follow-up (Bonner *et al* 1994) applied an appropriate complement of CBT techniques (i.e. cognitive, motivational as well as re-engaging the patient in *patient* desired activities), but was methodologically weak. It was described as a pilot only (Wessely 1991b); it was neither randomised or controlled - patients could receive anti-depressant medication in addition to the therapy provided.

Using the protocol that is outlined below, positive changes were found in social, private, work and leisure activities, as well as in psychological symptoms. Of those who agreed to participate (18 of the 50 did not; this was contrasted with 5/50 refusals among the previous patients referred by neurologists for CBT for other conditions) and who completed treatment (5 dropped out), there was an overall self-rated improvement in disability of 60%. Twenty eight percent of patients, applying strict criteria made complete recoveries; including these, 70% described themselves as “better” or much “better”. Consistent with the illness attribution findings reported above, it was found in this study that all of the patients who had an ‘equal physical and psychological’ attribution or a ‘mainly psychological’ attribution had a good treatment outcome, while 60% of the ‘physical’ or ‘mainly physical’ attribution had a good outcome.

In the four year follow-up study (Bonner *et al* 1994), it was found that 87% of the patients who completed treatment remained well, whereas only 13% of those who refused or did not complete treatment made a spontaneous recovery. With these positive results, however, one must bear in mind the ‘definition of ‘better’; the larger refusal rate (and any associated characteristics of the refusal group); the

confounding influence of the anti-depressants; and the lack of a control. Notwithstanding these caveats, the results appear encouraging and certainly warrant rigorous follow-up.

1.2.5.2.1.2 A Cognitive-Behavioural Model of CFS

Wessely and colleagues (1991b) propose that “for many patients, an initial infective trigger, with its associated myalgia and inactivity, begins a cycle in which both attributional and cognitive factors trigger avoidant behaviour. Avoidant behaviour itself sustains symptoms, as does any associated mood disorder, of whatever cause. The results explain much of the prolonged disability we associate with PVFS [CFS]” (p 314). The following model adapted from Wessely, helps explain a maintaining cycle of fatigue and depression symptomatology:

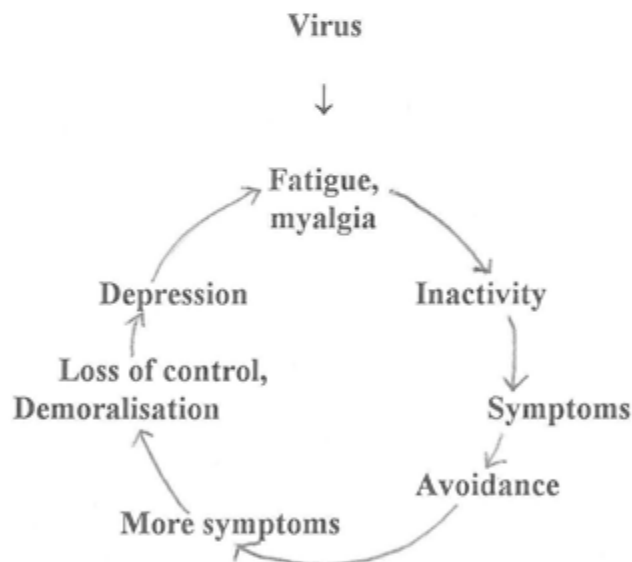


Figure 2 Cycle of responses in CFS (adapted from Wessely 1991, p 314-315)

If you superimpose components of the learned helplessness model, the following picture emerges:

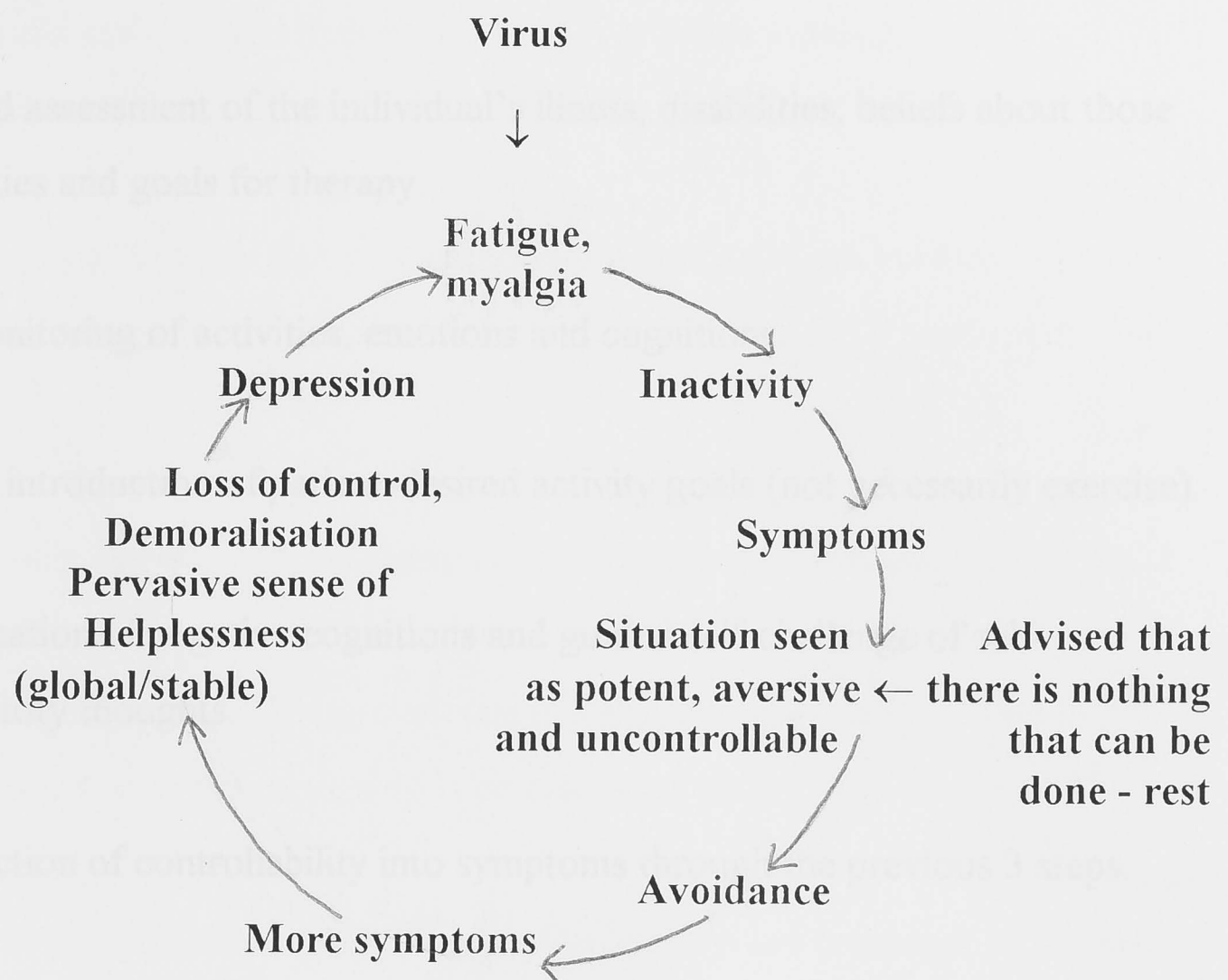


Figure 3 Cycle of responses in CFS - superimposing learned helplessness features (adapted from Wessely 1991, p 314-315)

1.2.5.2.1.3 Treatment Protocol

Wessely and colleagues are strong advocates of a cognitive behavioural approach to the management of CFS. They provide a chapter in “Post-viral Fatigue Syndrome” dedicated to explaining the rationale of CBT in CFS, the protocol that they have followed and the results obtained referred to above in the study by Butler and others (1991).

They explain that contrary to what many people think, the theoretical basis of CBT in CFS does not presuppose that the disorder has a psychological origin. It also must be stressed to patients (and some medical practitioners it is suggested - Wessely *et al* 1991b, p 317) that while CBT may help it does not suggest that ‘it is all in the mind and your symptoms are not real’. Both these premises must be explained and addressed initially to engage patients in treatment.

In summary, the protocol employed is as follows:

1. Detailed assessment of the individual's illness, disabilities, beliefs about those disabilities and goals for therapy.
2. Self-monitoring of activities, emotions and cognitions.
3. Graded introduction of patient-desired activity goals (not necessarily exercise).
4. Identification of negative cognitions and guided self-challenge of self-deprecatory thoughts.
5. Introduction of controllability into symptoms through the previous 3 steps.

Regarding step 1, Surawy and colleagues (1995) in their descriptive publication identified the following common illness beliefs:

- again, the illness was attributed to physical disease; patients resisted the suggestion that psychological factors may have contributed;
- psychological problems such as depression were regarded as indicating weakness, fault or blame;
- as well as being seen as unpleasant, symptoms were seen as a hallmark of a worsening of the disease;
- therefore any activity that exacerbated symptoms was considered harmful and as likely to lead to a relapse and was therefore avoided; rest was considered the best way to recover;
- patients were not concerned about having any alternative or additional serious occult disease;

- patients did not fear that their illness could be life threatening (as in hypochondriasis).

Patient records of activity also revealed that interspersed with periods of rest, patients would have bursts of exertion where they attempted to perform at pre-illness levels.

Consistent with these beliefs, Wessely *et al* (1991b) provide examples such as ‘I attempted to do more but feel exhausted, so I must have caused myself more muscle damage’ (p 311). The prevalence and negative role of ‘catastrophic beliefs’ in a CFS sample has already been discussed above (Petrie *et al* 1995).

In relation to physical activity, Wessely and colleagues are cognisant of the need to very gradually train unused muscles - to both avoid excessive pain and so as to break the avoidance cycle that otherwise arises.

In their uncontrolled trial of CBT (Butler *et al* 1991; Bonner *et al* 1994), a mean therapist involvement of 7.5 hours applied (range of 2 to 20) and therapy took place over a 4-6 week period.

The tendency to refer patients with physical maladies to psychological treatment as a last ditched effort is well documented (Salkovskis 1989). Given that there are no established treatments for CFS, this is unfortunate as “Most of the cases seen do not improve, give up their work and become permanent invalids” (Behan and Behan 1988). Again, it becomes clear that a replicated, controlled and rigorous treatment study is required.

1.2.5.3 MEASURES OF DEPRESSOGENIC THINKING

Several measures of depressogenic cognitions have been proposed, following the tenets of the particular cognitive theory from which they arose. These self report

measures have been primarily developed for use in research, rather than as diagnostic tools. They include:

The Attributional Styles Questionnaire (Seligman *et al* 1979)

The Automatic Thoughts Questionnaire (Hollon and Kendall 1980)

The Survey of Personal Beliefs (Demaria *et al* 1989)

The Dysfunctional Attitudes Scale (Weissman and Beck 1978)

As expected, the Attributional Styles Questionnaire (ASQ) is based on learned helplessness/ attribution theory. Subjects are asked to consider given life events and to assign causes for those events. They then rate the degree to which each cause is internal, stable and global (Parks and Hollon 1988).

The Automatic Thoughts Questionnaire (ATQ) has 30 items that assess frequency with which patients experience 30 depressogenic self-statements. It assesses 'stream of consciousness' and has been described as a state rather than stable measure (Parks *et al* 1988). It is considered a "cognitive concomitant (or aspect) of depressive symptoms" (DeRubeis *et al* 1990, p 864).

The Survey of Personal Beliefs (SPB) is based on the principles of Ellis's Rational Emotive Theory. It purports to measure the 11 irrational beliefs which are hypothesised to be causative of emotional distress (Demaria *et al* 1989). It contains 50 items which are scored for agreement on a 6 point Likert scale. It assesses an individual's predilection to operate from 'shoulds', 'awfulizing', 'I can't stand it itis', and negative global self worth statements.

The Dysfunctional Attitudes Scale (DAS) as its name suggests, is based on Beck's cognitive theory which states that when a person with dysfunctional (unhelpful to ones self) attitudes or beliefs is confronted with a stressful situation, their beliefs give rise to ongoing negative and self deprecating thoughts. The DAS has two parallel forms of 40 attitudinal statements that were written to tap underlying depressogenic assumptions - e.g. "I cannot be happy unless most

people I know admire me”, “If I fail at my work, then I am a failure as a person.” Items are scored for agreement on a 7 point Likert scale.

The DAS has been shown to distinguish depressed from non-depressed psychiatric patients and normal controls (Hollon *et al* 1986). It has also been found to successfully predict subsequent depressive episodes (Cane *et al* 1986). Under Beck’s cognitive therapy it would be predicted that the attitudes presented at the beginning of therapy would be changed by the end of it. Therefore it is the measure that most closely relates to the intent of cognitive therapy, as is widely applied alone or in conjunction with behavioural methods.

Weissman and Beck report internal consistencies of the two forms as 0.89 and high parallel form correlations (Rippere 1994). Factor analysis of Form A reveals two factors - ‘performance evaluation’ and ‘approval by others’ (Cane *et al* 1986). These factors have alternatively been called ‘perfectionism’ and ‘need for approval’ (Oliver and Baumgart 1985). These factors relate to Beck’s personality subtypes, ‘autonomous’ and ‘socially dependent’, for whom different events may trigger depression; these events are similar to those found in the two scale factors.

An interesting study (DeRubeis *et al* 1990) used four different measures of depressogenic cognitions, in an attempt to track cognitive and symptom change in cognitive and anti-depressant therapy. They found that the DAS as well as the ASQ (but not the ATQ) associated well with cognitive therapy outcomes for the depressed group.

Kuiper and colleagues (1989) explored the proposition that individuals with a large number of dysfunctional attitudes are cognitively vulnerable for depression, and that the depression is realised when stressful events mean that they cannot satisfy their own rigid conditions for self worth. The DAS was used as the measure of predisposing dysfunctional attitudes. They found that dysfunctional attitudes significantly moderated the relationship between certain stressful events and depressive symptomatology; as predicted, personal events which contained strong elements of disapproval from a significant other were especially

problematic for 'dependent' vulnerable individuals, resulting in significant depressive symptomatology (most events related to interpersonal issues so there was little opportunity to look at depression vulnerabilities relating to high standards). In short, those with high DAS scores, and who encountered stressful events, obtained the highest depression scores.

If patients with CFS were found to have depressogenic attitudes *in addition* to the often disabling illness beliefs mentioned above (e.g. 'any fatigue or discomfort means that my condition is worsening and I am doing damage'), there would be a further basis for proposing CBT as a treatment, at least with some individuals. If not, however, the cognitive component of CBT would, in many cases, just need to address maladaptive illness beliefs.

1.2.6 HIGH ACHIEVEMENT, HIGH STANDARDS AND CFS

1.2.6.1 The Folklore

There is much suggestion that CFS sufferers have been high achievers who set high standards for themselves. This has perhaps contributed to the pejorative media term 'yuppie flu' (MacLean and Wessely 1994).

Most studies have reported that their CFS subjects were well educated (Shafran 1991; Woodward 1993), although Lloyd found in their prevalence study of an Australian population that the social status of the CFS subgroup was consistent with that of the population studied (Lloyd *et al* 1990).

A high incidence of CFS has been reported amongst elite athletes (Puffer and McShane 1991). In Woodward's study (1993) 19 of the 50 study participants had previously been very active and fit, engaging daily in aerobic activities and sports. Riley and colleagues (1990) similarly reported high pre-morbid activity levels although Lewis and co-workers (1994) found that their CFS group

reported similar pre illness levels of activity to their comparison group of patients with irritable bowel syndrome. Woodward (1993) states that “individuals who have developed this illness [CFS] have characteristics in common. They have been active, productive and conscientious people.” (p 2).

The observation and interviews with over 100 CFS patients in the study by Surawy and colleagues (1995) “typically revealed a pre-morbid personality characterised by a marked achievement orientation, perfectionism, and high standards for work performance, responsibility and personal conduct. Their pre-morbid lifestyles were similarly characterised by prolonged striving to meet both their own high standards and the expectations of others.” (p 537). Surawy also observed that CFS patients placed a high value on being seen to be in control and ‘putting on a brave face’.

A newspaper article written by a CFS sufferer and reprinted in Chameleon, the local ME/CFS Society newsletter states “It seems that I am your typical CFS sufferer - mid-20s, female and, a perfectionist” (Leisk, 1996).

While the pattern of high standards and high pre-morbid achievement in CFS patients have been noted in the literature, it remains untested and unquantified.

1.2.6.2 The Relationship Between High Standards and Depression

Surawy *et al* went on to say that the notion that CFS sufferers are perfectionists and high achievers is not new and draw a parallel with depression research and the characteristics of Beck’s ‘autonomous personality’. Beck suggests that the manifestation of depression in autonomous/ achievement orientated individuals is characterised by the rejection of help, pessimism about recovery, and a great concern about not being able to perform and meet the individual’s usual high standards (Beck *et al* 1979).

Burn (1980) describes perfectionists as people whose standards are high beyond reach or reason and who try unremittingly to achieve those impossibly high standards; importantly, they perceive their own worth, almost entirely in terms of productivity and accomplishment.

Surawy and others (1995) propose a cognitive model to explain the aetiology of CFS:

1. typically a predisposition which includes high standards and control of emotions both in attitude and behaviour;
2. followed by a critical incident(s) involving excessive demands or reduced ability to meet demands (e.g. negative life events or a viral illness), leading to:
 - behaviourally - try harder and don't complain;
 - emotionally - frustration and distress;
 - symptomatology - fatigue and autonomic arousal;
 - thoughts - 'why am I not coping?' and 'I must be physically sick'.

The current author has a greater interest in possible maintenance of any depression symptomatology in CFS rather than wishing to 'buy into' what Wessely has called the "futile 'organic versus psychological' polemics" (1991, p 669). While it is clearly important to establish what causes CFS for purposes of prevention; for practical illness management; as well as for academic gratification, it will probably be some time, if at all, before the cause or causes are clearly identified. In the meantime, there are a number of people reporting for primary care who are experiencing a number of distressing and debilitating symptoms. Any information that can be gleaned in the here-and-now to assist these individuals in managing their illness is of paramount importance.

Surawy and colleagues (1995) proposes the following maintaining cycle of chronic illness, consistent with their cognitive model of the aetiology of CFS. The

model can be modified to provide an explanation of the perpetuation of depression in CFS, without having to make any assumptions about the aetiology of the illness:

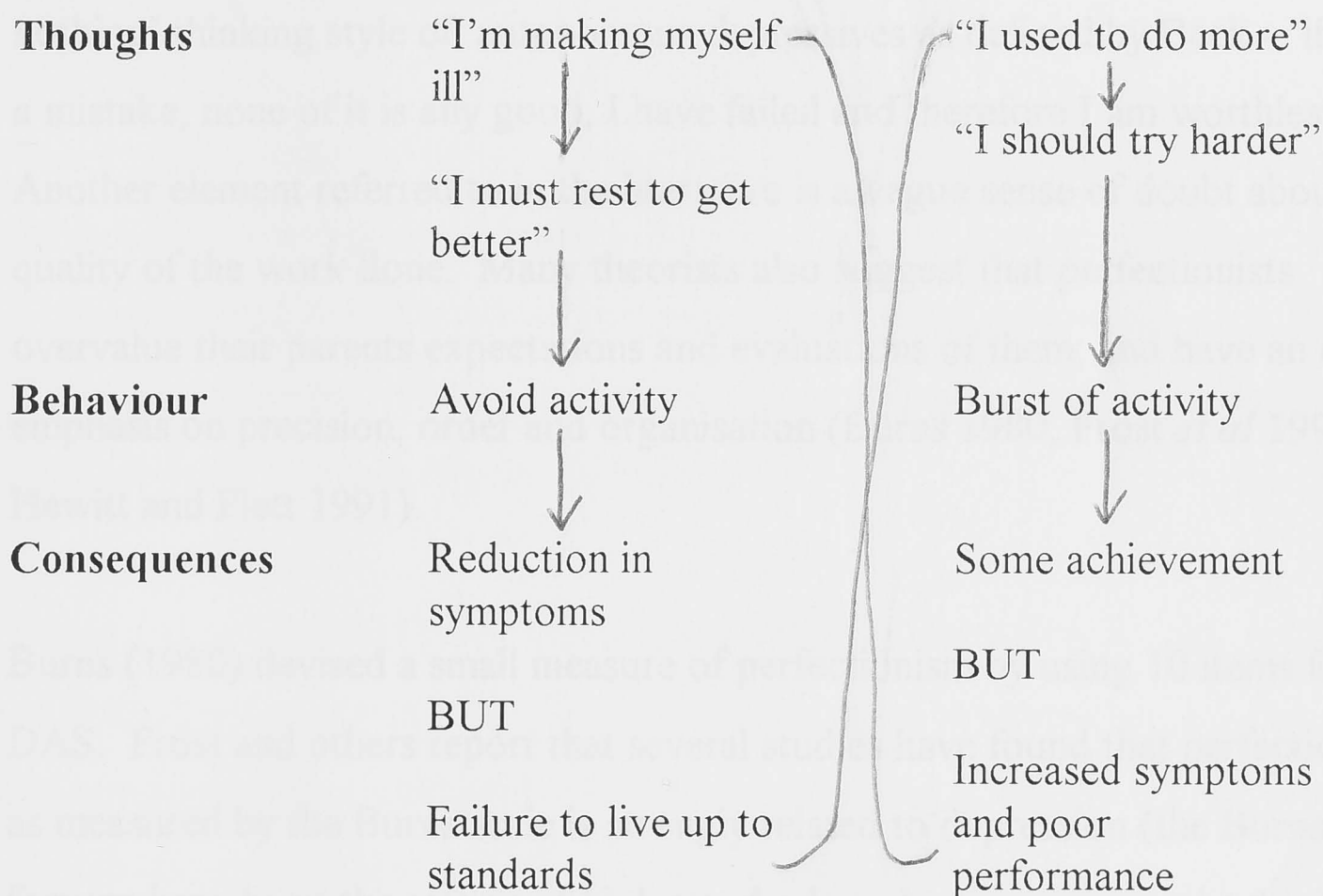


Figure 4 The maintenance of depression in CFS (From Surawy *et al* 1995, p 539)

1.2.6.3 Measures of Perfectionism

Perfectionism and related constructs such as need for achievement, and Type A behaviour have been studied extensively. Perfectionism is alternatively seen as a *modus operandi* for achieving goals at a superlative level and as being linked to negative outcomes such as feelings of failure, procrastination and low self esteem. It has also been linked to numerous conditions such as alcoholism, erectile dysfunction, irritable bowel syndrome, anorexia, Type A coronary-prone behaviour, anxiety disorders and depression (Hewitt and Flett 1991; Frost *et al* 1990).

Frost and colleagues suggest that perfectionism and its association with psychopathology arise not just through the setting of high standards, but through

“high standards of performance *which are accompanied by tendencies for overly critical evaluations of one's behaviour*” (1990, p 450).

Key ingredients of perfectionist behaviour are excessive concern over mistakes, even small ones. Burns (1980) suggests that this is an example of the ‘all-or-nothing’ thinking style of autonomous depressives as defined by Beck - ‘if I make a mistake, none of it is any good, I have failed and therefore I am worthless’. Another element referred to in the literature is a vague sense of doubt about the quality of the work done. Many theorists also suggest that perfectionists overvalue their parents expectations and evaluations of them; and have an over emphasis on precision, order and organisation (Burns 1980; Frost *et al* 1990; Hewitt and Flett 1991).

Burns (1980) devised a small measure of perfectionism by using 10 items from the DAS. Frost and others report that several studies have found that perfectionism, as measured by the Burns scale is strongly related to depression (the Burns scale focuses heavily on the setting of high standards and concern over mistakes)(Burns 1980; Frost *et al* 1990). In a series of studies by Frost and colleagues (1990) it was found that it was concern over mistakes, rather than the setting of high standards that was central to the ‘neurotic’ sense of perfectionism; it was also the dimension that was most closely related to symptoms of psychopathology. The subscale ‘doubting of actions’ also associated with psychopathology. More specifically, Frost’s overall perfectionism scale, concern over mistakes and doubting of actions each associated with what Blatt *et al* (1976) termed ‘self-critical depression’, rather than relating uniquely with the other dimension of depression in Blatt’s schema, ‘dependency depression’. (These dimensions seem analogous to what Beck terms ‘autonomous depression’ and ‘socially dependent depression’, respectively).

It could be hypothesised that if CFS patients have typically been high achievers, and then because of a viral illness or other precipitating factor can no longer physically and mentally achieve to the same standards, that ensuing levels of depression would be high. Indeed, it could be expected that if there is a

predisposition toward perfectionism in CFS sufferers, then ensuing levels of depression would be higher than levels found in comparable chronic illnesses where no such predispositions are found.

1.2.6.4 Type A Behaviour

The Type A behaviour pattern, which has the following elements - extreme achievement striving, time urgency, hostility and hard driving behaviour has long been associated with the risk of coronary heart disease (Rosenman *et al* 1975; Bernard and Krupat 1994). The behaviour has also been linked to a number of other physical illnesses (Rime *et al* 1989).

Lewis and colleagues (1994) conducted a study in which they looked at the levels of Type A behaviour in a sample of CFS patients. They hypothesised that given the supposed pre-morbid profile of CFS patients that is, that they were previously high achievers, and that ambitious people could be expected to be hard hit by a disorder that prevents them from attaining their high goals, high levels of Type A behaviour should be prevalent in CFS patients. They talked of the pre illness highly “pressurised lifestyle” that has been described in CFS patients (p 668).

They used the Bortner scale to measure Type A behaviour (Bortner 1969). This measure has, however, been found to have unacceptably low internal reliability and in fact taps two dimensions - speed and competitiveness. The latter dimension includes ‘hard-driving behaviour’ (Edwards *et al* 1990).

Their study also looked at coping behaviour in the illness and the availability of social support. They found that the global construct of Type A behaviour was not relevant in CFS (probably not surprising given the findings of poor reliability and the limited coverage of the instrument found in Edwards study). However, they did find that the component ‘hard-driving behaviour’ was characteristic of the CFS group. This finding is consistent with the coping style described by Woodward in her study (1993) - CFS sufferers tended initially to respond to their

illness with denial and defiance and tended to 'push-through' despite their fatigue and other symptoms.

1.3 A CASE FOR EXAMINING THE ROLE OF COGNITIONS IN THE MAINTENANCE OF DEPRESSION IN CFS

While there is much to be discovered and unearthed in understanding the pathogenesis of CFS, the current situation is that there are many individuals suffering from this illness, with little on offer in the way of treatment. It may be some time before enough is known about the illness to provide the much sought after 'magic bullet' cure. Indeed with some illnesses such as multiple sclerosis, even when the origins are ascertained by years of research, little other than illness management and treatment of the symptoms can be offered to the patient.

In the absence of any established treatment it would seem imperative to consider the known elements of the illness and to develop a treatment protocol that fits best with that information; adjustment of the approach as further information comes to light would be essential. Ultimately, the most efficacious treatment may have contributions from each of the scientific areas of interest - eg particular infectious and immunological treatments may be prescribed; healthy diets and nutritional supplements may be incorporated; balanced exercise regimes along with sufficient rest periods may be involved; and the author would suggest, in the context of the current research, that perhaps cognitive therapy may have a role in assisting the patient in managing their illness and minimising any resultant depression.

Recent research of psychological factors in CFS can be summarised as follows:

- There is an association, some postulate causal, others resultant, between CFS and depression;

- The best predictor of prognosis is the attribution of the illness - an external or physical attribution being associated with poorer prognosis. Demographic details or illness factors do not correlate with outcome;
- Having an external illness attribution, while associated with poorer prognosis, protects self esteem;
- There is some suggestion that catastrophic thinking in CFS patients is associated with greater functional impairment;
- Cognitive models have been proposed. Central to these is the illness belief that activity will exacerbate symptoms which leads to avoidance of activity, which in turn produces further symptoms as well as depression;
- Folklore presents a portrait of CFS sufferers as previously active and as having had high standards and perfectionist tendencies; and
- Cognitive behaviour therapy trials have been of mixed quality and have had mixed outcomes.

Putting together the psychological constructs found in the literature, the following cognitive and behavioural sequelae is postulated:

A viral trigger seems to be involved for many people

The virus involves symptoms of fatigue and myalgia which continues for a prolonged period

The symptoms of fatigue and myalgia provide a disincentive for activity

Self-help groups and the medical profession have typically advocated rest until the symptoms dissipate

CFS patients have incorporated these beliefs about the benefits of rest and the negatively perceived implications of being fatigued after activity

Following long periods of rest, body deconditioning occurs so that the patient is very unfit and exercise is effortful

Further avoidance of activity occurs

Because CFS sufferers tend to have been active, high achievers, with high standards, the lack of activity and reduction in achievements have activated depressed 'autonomous' cognitions regarding self worth

Depression associated with being unable to achieve at previous levels exacerbates the fatigue experienced

This model incorporates hypotheses of both Wessely's work (1991) and Surawy and colleagues' studies (1995); it includes the illness beliefs and avoidance factors of both, as well as the cognitions regarding not living up to high standards postulated by Surawy and others. It is the objective of the current research to test this model, with particular focus on patients' cognitions about the illness. At this stage, the particular illness beliefs postulated have not been assessed by empirical research.

Further, the current study attempts to broaden the model and thereby add information to the 'melting pot' by studying general depressogenic thinking among CFS sufferers. It could be postulated that, if the folklore about high

achievement, high standards and perfectionism are correct, a particular profile of depressed thinking would develop in this illness. This profile would not be expected so much to reflect the depressogenic construct of social dependency/approval by others ('everyone must love me otherwise I am worthless'), but rather the construct that Beck describes as the 'autonomous' thinker ('I must do things at a superlative level otherwise I have failed and I am worthless'). If this pattern of depressogenic thinking is found in a sample of CFS sufferers, then future treatment could incorporate cognitive therapy appropriately tailored to both negative illness beliefs and broader dysfunctional assumptions.

There are two key approaches that could be adopted to test these hypotheses. The first would be to conduct a treatment trial in which illness beliefs were challenged under a cognitive protocol, along with any depressogenic cognitions. A treatment trial, and preferably a pull-apart model in which the efficacy of different components were assessed, is beyond the scope of this research. The second approach is to test whether there is evidence of negative illness beliefs and depressogenic thinking in a sample of CFS afflicted subjects. The latter is the approach adopted in the current study.

This aim of the current research translates into the following specific hypotheses:

1. CFS sufferers are high achievers and are achievement orientated

- a) CFS sufferers have achieved higher levels of education, occupation and sporting prowess than their peers.
- b) Further, relative to their parents' educational level and occupation, CFS sufferers have achieved at higher level than comparison groups.
- c) CFS sufferers report high levels of pre-illness achievement-oriented behaviour.

2. CFS sufferers have depressogenic thinking consistent with the 'autonomous'/performance evaluation factor

- a) CFS sufferers have higher overall levels of depressogenic thinking than their peers, but not higher than depressed individuals.
- b) CFS sufferers have higher levels of depressogenic thinking in the 'performance evaluation' factor than their peers, but not higher than depressed individuals.
- c) CFS sufferers have high levels of the performance standards proposed by Surawy et al (1995).

3. CFS sufferers have a tendency to perfectionism

- a) CFS sufferers have high levels of perfectionism.
- b) CFS sufferers have high levels of perfectionism in the aspects associated with psychopathology (concern about mistakes; doubts about actions).

4. Illness severity is associated with the level of depression and depressogenic thinking

- a) Greater severity of CFS symptoms is associated with higher levels of depression.
- b) Greater severity of CFS symptoms is associated with higher levels of depressogenic thinking.

5. Attitudes to the Illness are associated with levels of depression and depressogenic thinking

- a) An internal illness attribution is associated with higher levels of depression.
- b) An internal illness attribution is associated with higher levels of depressogenic thinking.
- c) CFS illness beliefs are associated with higher levels of depression
- d) CFS illness beliefs are associated with higher levels of depressogenic thinking.

2. METHODOLOGY

2.1 DESIGN

This study has a non-experimental design and incorporates both clinical and normal groups. It utilises the collection of data by means of a questionnaire. As predicated by the above listed hypotheses, it involves the examination of a series of between groups comparisons on achievement variables; depression and depressogenic thinking variables; and measures of perfectionism. It also requires the examination of associations between depression and depressogenic thinking and a series of other variables - illness severity, stage of illness, illness attribution and illness beliefs. The design being cross-sectional in nature and non-experimental, does not permit the making of judgements about the causality of any of the latter associations.

The study group comprises subjects with a diagnosis of CFS. In addition, a clinical control group of people given a diagnosis of depression was chosen for the study. This clinical sample was selected because of the high concordance of depression in a majority of CFS patients and the interest of the current study in exploring depressogenic thinking and particularly, cognitions regarding performance evaluation and perfectionism. An exploration of similarities and differences between these two groups in terms of depression associated thinking was considered helpful in guiding any future cognitive therapies with individuals suffering from CFS. A 'healthy' control group was also chosen to provide a benchmark for comparisons between the two clinical groups.

2.2 PROCEDURE

2.2.1 APPROACH

As it was the intention of this study to explore and generalise any depressogenic thinking patterns amongst people with CFS, it was considered essential that 'typical' individuals with this diagnosis be accessed. In terms of demographic factors such as age and educational qualifications, Canberra and surrounds, the location of the study, has a younger and better educated profile (ABS 1991; 1995). Given this restriction, it was considered important that the resultant sample was not further biased in terms of education or illness severity.

It has been argued that people who are members of support groups or associations tend to be better educated and arguably more articulate (Lewis and Wessely 1992). For this reason, it was preferred that subjects were not accessed from the local ME/CFS Society³.

Similarly, it is suggested that study subjects that are obtained from specialist tertiary institutions⁴ tend to represent the more extremely ill end of the spectrum, or a higher level of chronicity. Most published studies have tended to employ hospitalised patients⁵ (McDonald et al 1993) and for this reason, their results cannot be applied to primary care (Wessely *et al* 1989). Furthermore, Canberra and surrounds does not boast such a specialist CFS medical institution, although a myriad of specialists are actively involved in the diagnosis and treatment of patients with CFS.

³ The ACT ME/CFS Society, did, however, call a special meeting to hear about the research and provided its endorsement of the study.

⁴ Such as the Prince Henry Hospital in Sydney.

⁵ All of the studies discussed in the introduction, with the exception of the prevalence studies (Lloyd et al 1990; Pawlikowska et al 1994) and the McDonald et al primary care study (1993) involved either secondary or tertiary care - specialists or specialists' referral centres.

A third key factor influencing the choice of *entre* to study subjects was the need to ensure that subjects had been clearly diagnosed with the Syndrome. As discussed more fully in the introduction, the incidence and symptoms of chronic fatigue and chronic fatigue *syndrome* are quite different, with the latter forming a discrete and much smaller subset of the former; it was considered important that subjects were not self diagnosed or misdiagnosed. Given these factors, the natural choice was to access study subjects through medical practitioners operating in general practice - representative subjects could be obtained in terms of illness severity and education level, and subjects would have already been through a formal medical diagnosis.

A clinical control group comprising individuals given a diagnosis of depression, as well as a normal control group - 'healthy' individuals, were included in the study. It was considered important that the two control groups be accessed through the same method as the CFS subjects to assist with comparability.

2.2.2 CRITERIA USED

2.2.2.1 CFS

As discussed in the introduction, previous studies have used either the North American, Holmes 1988 definition of CFS (Holmes *et al* 1988), the UK definition (Sharpe *et al* 1991), or the Australian working definition (Lloyd *et al* 1988;1990). However, due to differences between these criteria and even application within each set (Schlurderberg *et al* 1992), a new set was developed by the International Chronic Fatigue Syndrome Study Group in 1994 (Fukuda *et al* 1994). These criteria purport to provide a more systematic and comprehensive approach toward data collection; and they were developed and endorsed by a vast collection of the pre-eminent researchers in the CFS domain (the Study Group reads like a Who's Who of the field!) (Fukuda *et al* 1994). These criteria were adopted in the present study and were presented to the General Practitioners:

1. Fatigue (clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is of new or definite onset (has not been lifelong); is not the result of ongoing exertion; is not substantially alleviated by rest; and results in substantial reduction in previous levels of occupational, educational, social, or personal activities).
2. Four or more concurrent symptoms which are persistent or recurrent during six or more consecutive months and which do not predate the fatigue:
 - self reported impairment in short term memory (severe enough to cause substantial reduction in previous levels of occupational, educational, social or personal activities)
 - sore throat
 - tender cervical or axillary lymph nodes
 - muscle pain, multijoint pain with or without joint swelling or redness
 - headaches of a new type, pattern or severity
 - unrefreshing sleep
 - post-exertional malaise of more than 24 hours

Diagnosis is **excluded** if there is:

1. Any active medical condition that can explain the presence of chronic fatigue such as untreated hypothyroidism, sleep apnea and narcolepsy, and iatrogenic conditions such as side effects of medication.
2. Any previously diagnosed medical condition whose resolution has not been documented beyond reasonable doubt and whose continued activity may explain the chronic fatiguing illness. Such conditions may include previously treated malignancies and unresolved cases of hepatitis B or C virus infection.

3. Any past or current diagnosis of a major depressive disorder with psychotic or melancholic features; bipolar affective disorders; schizophrenia of any subtype; delusional disorders of any subtype; dementias of any subtype; anorexia nervosa; or bulimia nervosa.
4. Alcohol or other substance abuse within 2 years before the onset of the chronic fatigue and at any time afterward.
5. Severe obesity as defined by a mass index [body mass index = weight in kg/(height in metres)²] equal to or greater than 45.

2.2.2.2 Depression

ICD-10 criteria (World Health Organisation, 1992) for a single episode or recurrent depression were used to define the depressed clinical control group. A moderate to severe level of depression was proposed as the symptomatology extent and effect on functioning at this level was comparable to the symptoms and effect on functioning of CFS; mild depression was considered insufficient. These criteria, although consistent with the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association 1994) criteria for depression were used as they are more widely adopted in the medical field. Thus the criteria presented to GPs were as follows:

1. Duration of at least two weeks.
2. At least two of the following symptoms:
 - depressed mood
 - loss of interest and enjoyment
 - increased fatiguability

3. At least three of the following symptoms:

- reduced concentration
- reduced self esteem and self confidence
- ideas of guilt and unworthiness
- bleak and pessimistic views of the future
- ideas or acts of self-harm or suicide
- disturbed sleep
- diminished appetite

4. Usually considerable difficulty in continuing with social, work or domestic activities.

2.2.2.3 Healthy

Doctors were also provided with criteria to define the ‘healthy’ subjects. The intention of this control group was to provide a base of attitudes and behaviour in ‘normal’ GP patients, to contrast with attitudes and behaviour in patients with CFS or depression. The criteria provided to GPs were:

1. No ongoing physical or mental illness.
2. Patients would be suitable if they are attending for a single, casual and non-urgent matter which is unlikely to require continuing medical care eg a short term common virus, a minor physical injury, contraceptive medication, routine checkups etc.
3. Do not include any patients with minor ailments who you consider may be hypochondriacal.

Doctors were also invited to ring if they were unsure whether to include a patient. No such enquiries were made.

2.2.3 PROCEDURE

The design and procedure were approved by the Australian National University Ethics in Human Experimentation Committee in September 1995.

General Practitioners in the Canberra district were invited to participate in the study via an invitation that was inserted into the ACT Division of General Practitioners newsletter in November 1995. Of the 305 registered GPs, 23 replied indicating that they were willing to participate and a further 9 replied indicating that they did not wish to participate. Personal follow up by mail of some of the GPs (those with readily available addresses) who had not replied yielded a further 3 GP participants.

A package of material (see copy at Attachment 1) including the questionnaires was dropped to each GP practice during the period February to August of 1996. The package comprised:

- 'CFS' questionnaires
- 'Depression' questionnaires (typically 5-10 of each, depending on the doctor's patient load)
- 'Healthy' questionnaires
- Information for Doctors re CFS Research
- Copy of the invitation to doctors
- Criteria for Diagnosis of CFS
- Criteria for Diagnosis of Depression
- Criteria for Healthy Group
- Basic Demographic Details of Those Approached with Questionnaire

The questionnaires were placed in addressed, return paid envelopes. A brief slip was attached to each envelope for the participating doctors to endorse the

research to their patients. Doctors had the choice of either handing the questionnaire to patients as they saw them for surgery appointments, or posting them *en masse* (stamps were provided). All but one doctor took the former approach. Doctors were followed up by letter and by phone to check that instructions were clear and to keep track of the numbers being handed out.

The questionnaires had a cover sheet which provided some background on the research as well as the instructions for completion and return of the questionnaire. A consent form which required the subjects signature was also attached to the questionnaire; it was detached from the questionnaire (to ensure confidentiality and anonymity) on its return to the researcher. Subjects were also given the option of being informed of the results at the completion of the study - if this option was taken up, subjects provided their name and address for later mailing.

A pilot run of the procedure and of the questionnaire content itself was conducted in December 1995. Two of the researcher's local GPs volunteered for this role. The procedure was found to be satisfactory while the questionnaire required rewording of one question to add further clarification.

At the end of the data collection phase, all unused material and the demographic details of patients provided with a questionnaire were collected from GPs.

2.2.4 SUBJECTS

GPs were asked to handout the questionnaires for patients with CFS and depression, if the patient met the diagnostic criteria provided. The GPs were then asked to handout questionnaires to healthy patients as defined in the study, being cognisant of the basic demographic composition of the patients provided with CFS and depression questionnaires. In this way it was hoped that the healthy control would be crudely matched to the clinically diagnosed groups in terms of basic demographic detail.

Altogether, 39 'CFS' questionnaires were returned, although one return was not used as the respondent was too young. This provided a sample of 31 women, 7 men. Thirty 'depression' questionnaires were returned, although two were not included as one respondent was too young and another indicated that she had not had depression for some years. The resultant group comprised 18 women, 9 men and 1 sex unspecified. Thirty three 'healthy' questionnaires were returned, giving a sample size of 28 women and 5 men.

80 or 75% were interested in receiving a copy of the results when the study was complete. Of these 36 were from the CFS sample, 22 from the depression sample, and 22 from the healthy sample.

It is difficult to calculate the return rate of the questionnaires as some doctors 'lost' the questionnaires and only one doctor completed the demographic details checklist. However, of the approximately 800 questionnaires handed to the 26 doctors, some 500 were later collected unused. This provides a conservative return rate of 33% of the questionnaires and probably a significantly higher rate of return, given that a number of uncompleted questionnaires were misplaced by doctors.

2.2.5 QUESTIONNAIRE

To answer the central questions relating to CFS and any associated depressogenic thinking, the questionnaire was divided into three main parts - demographic and achievement data; illness data; and indications of behaviour, attitudes and cognitions. A final section asked clinical respondents about their experience with counselling.

2.2.5.1 Demographic and Achievement Data

Demographic detail of age, sex, occupation, educational qualifications, and marital status were obtained. The format matched the 1991 Census format developed by the Australian Bureau of Statistics (ABS 1991).

To provide some measures to assess Hypothesis 1 that individuals with CFS tended to be high achievers, information was also obtained for the purpose of estimating achievement. A broad index of achievement could be developed by examining sporting achievement; educational and occupational status in relation to same age peers; and gain in educational and occupational status relative to subjects' parents.

2.2.5.2 Illness Data

The illness data collected was comprehensive. It included illness symptomatology and severity; duration and stage of illness; illness attribution; level of support and criticism during the worst part of the illness; functional impairment; and a measure of psychopathology.

2.2.5.3 Illness Symptomatology

A full symptom checklist of 27 items was developed, closely based on the new definition of CFS developed by the International Chronic Fatigue Syndrome Study Group (Fukuda 1994); and by the two previously widely used sets of criteria by Holmes and by Lloyd (Holmes *et al* 1988; Lloyd *et al* 1990; Rikard-Bell *et al* 1992; Blakely *et al* 1991). Further, the literature on the development of valid fatigue measures was canvassed for additional relevant items (Ray *et al* 1992; Chalder *et al* 1992; Schwartz *et al* 1993). As the latter fatigue measures

were designed to measure more broadly than fatigue encountered in CFS, few additional items were generated from these instruments.

To ensure that the symptom checklist was also comprehensive and relevant for subjects in the depressed control, symptoms of depression were also incorporated into the list. These were obtained from the diagnostic prescriptions of ICD-10 (World Health Organisation 1992) as well as DSM-IV (American Psychiatric Association 1994); many of the symptoms overlapped.

Subjects were also invited to indicate if they experienced further illness symptoms.

Subjects were asked to indicate the extent of the symptoms using a four point Likert scale - never (0), occasionally (1), frequently (2), and everyday (3) (Blakely *et al* 1991; Petrie *et al* 1994). The reference time frame was the previous month. Other studies have used a variety of scales, with a four point Likert scale being typical, and those that indicate a reference time frame often indicate one month (Ray *et al* 1992a; Ray *et al* 1992b; Chalder *et al* 1993; Schwartz *et al* 1993). A reference time frame of one month seemed appropriate given the oft described waxing and waning of symptoms of CFS (Woodward 1993).

2.2.5.4 Duration and Stage of Illness

The clinical subjects were asked to indicate which year they first received their diagnosis of CFS, or in the case of the depressed sample, depression. They were also asked how long they had been ill with CFS or depression as appropriate.

It was considered important to know which stage of the illness subjects thought they were at to determine if there was any association between stage and the attitudes, behaviours and cognitions. Thus they were asked to indicate which stage of the illness they thought that they were at - 'beginning', 'in its midst', 'recovery' or 'don't know'. Previous studies have not typically ascertained this perception, however, individuals with CFS attending the specially convened

meeting of the ME/CFS Association to discuss the current research suggested that behaviour and attitudes varied with the stage of illness.

2.2.5.5 Illness Attribution

Given the controversy regarding the attribution of individuals with CFS to a physical cause; the found association between a physical attribution and a poorer illness outcome; and the possibility that there is an association between the illness attribution and behaviour and cognitions, the subject's illness attribution was determined in the questionnaire. Subjects were asked to indicate whether their condition was 'definitely physical', 'physical but psychological factors have some importance', 'equally physical and psychological', 'mainly psychological', or 'don't know'. This scale, although asymmetric was adopted to permit comparison of these results to previous studies (Schweitzer *et al* 1994; Butler *et al* 1991; Wood *et al* 1991; Powell *et al* 1990; Surawy *et al* 1995).

2.2.5.6 Support and Criticism

Subjects were asked to indicate when the worst six months of their illness had occurred, and in this context, to rate various people in their lives in terms of the level of criticism and support that they had provided. Of interest here was the perceived level of self-criticism and self-support, so as well as rating the perceived response of partners, mothers, fathers, children, other family members, friends, colleagues, doctors and acquaintances, subjects were asked to assess their own level of support and criticism to themselves. A four point Likert scale was used - not at all critical (0), a little critical (1), quite critical (2), very critical (3), as well as a 'not relevant' option. Similarly, the range of people in subjects' lives were rated in terms of - completely unsupportive (0), a little supportive (1), quite supportive (2), very supportive (3), and a 'not relevant' option was also provided (Ray 1992).

2.2.5.7 Functional Impairment

In addition to symptomatology, it is clearly important in assessing the severity of an illness to determine the impact that the illness is having on daily functioning. Simple measures of functional impairment such as the Sickness Impact Profile have been developed and used in the study of CFS (Petrie *et al* 1995; Wessely *et al* 1989; Ray 1992; Ray *et al* 1993; Sharpe *et al* 1992; Bonner *et al* 1994) and have their origins in scales developed for other chronic illnesses⁶. Such a measure was incorporated into the questionnaire. It asked subjects to rate how much their illness (either CFS or depression, as appropriate) had affected them in the areas of family/home management; ability to work; self-care; social leisure; and private leisure. Each of these domains were defined for the subjects. A nine point scale was provided ranging from a response indicating that the illness affected them in that area 'not at all' (0), through to 'very severely - cannot do it' (8).

2.2.5.8 Psychopathology

A range of measures of psychopathology have been used in studies on CFS - the General Health Questionnaire (Blakely *et al* 1991; Schweitzer *et al* 1994; Pawlikowska *et al* 1994; Wessely *et al* 1989; Bonner *et al* 1994); the Beck Depression Inventory (Schweitzer *et al* 1994; Blakely *et al* 1991; DeLuca *et al* 1993; Grafman *et al* 1993); the Center for Epidemiologic Studies Depression Scale (Krupp *et al* 1993); the Middlesex Hospital Questionnaire (Smith *et al* 1993); psychiatric interviews such as the Present State Examination (Wood *et al* 1991; Katon *et al*); the Structured Clinical Interview (Hickie *et al* 1990) and the revised Clinical Interview Schedule (McDonald *et al* 1993). However, these instruments, particularly the ones partly or expressly assessing depression, have not been developed to take into account physical illnesses with associated symptoms of fatigue and other somatic complaints. It has been argued that their results have accordingly given a spuriously high number of cases of depression in hospitalised and otherwise physically ill individuals (Zigmond and Snaith 1983;

Ray *et al* 1993). In an attempt to control for physical illness, Wessely and Powell in a 1989 study of CFS removed the criterion of fatigue from their application of the Research Diagnostic Criteria (Ray 1991).

Alternatively, the Hospital Anxiety and Depression Scale (HADS) which was developed by Zigmond and Snaith in 1983 may be applied to overcome these problems of comorbidity. It is a brief self report measure with 14 items; these provide two scales one for depression and the other for anxiety. It has been found to have good reliability. Internal consistency is quite high - Cronbach's alpha of 0.93 for the Anxiety scale and 0.90 for the Depression scale were obtained in a sample of patients with cancer; test-retest provides correlations of 0.89 for the Anxiety scale and 0.92 for the Depression scale. (Zigmond and Snaith 1983). Validity in chronically ill patients such as patients with cancer and patients with chronic pain has been found to be acceptable and higher than in other non interview, depression measures (Tyrer 1992; Razavi *et al* 1990; Moorey *et al* 1991; Lewis *et al* 1990). It has also been positively evaluated in a psychiatric context (Hamer *et al* 1991; Bell *et al* 1991).

The HADS has become more widely used in studies of CFS given its lesser focus on somatic symptoms (Ray *et al* 1993; Bonner *et al* 1994; Sharpe *et al* 1992). For these reasons, the HADS was incorporated into the present questionnaire as a valid indicator of depression and anxiety amongst subjects with a diagnosis of CFS, subjects with a diagnosis of depression and among healthy subjects.

2.2.5.9 Behaviour, Attitudes and Cognitions

This section of the questionnaire was divided into three parts. The first was designed to elicit information about the individual's style of behaviour prior to developing CFS (or depression as appropriate for the clinical control group); the second was designed, more specifically to elicit attitudes toward the illness itself;

⁶ For example, the Pain Disability Index used by the Woden Valley Hospital Pain Clinic

and the third, the key component of this section, was to elicit any indications of depressogenic thinking.

2.2.5.9.1 Behaviour

As discussed in the introduction, there is much suggestion, if not cold, hard data, that people diagnosed with CFS led busy, active and ‘driven’ lives prior to developing the illness. Accordingly, a measure of pre-illness behaviour incorporating the ‘hard-driving’ component of the Bortner Scale, a measure of overall Type A Behaviour, was extended and included (Lewis *et al* 1994; Edwards *et al* 1990; Bortner 1969).

The Lewis study discussed above found that while the Bortner Scale did not well discriminate their CFS subjects from their controls, the CFS group were characterised by, at least the self-perception, of having been ‘hard-driven’ before the onset of their illness. The eight ‘hard-driving’ items that were developed for the present study incorporated characteristics of the Woodward sample of CFS sufferers (1993); they could also be used, and particularly the item on achievement, to help assess Surawy *et al*’s contention that their CFS patients had premorbid lifestyles characterised by “prolonged striving to meet both their own high standards and the expectations of others” (1995, p 537).

The items were placed on a 7 point scale ranging from completely identifying with the behaviour, to indicating that they identified with the opposite behaviour. The items were randomised with presentation of the extremes - that is, sometimes one end of the scale indicated hard-driven behaviour, while sometimes it indicated relaxed or ‘easy-going’ behaviour:

Never rushed	Always rushed
Would go ‘all out’ to get things done	Would not try to get lots done
Did lots in a day	Did little in a day
Slowly got things done	Quickly got things done
Prided self on level of achievement	Not focused on achieving

Would stop, rest and relax	Tended to 'push through' and not stop
Led a busy, active life	Was not busy or active
Put in minimal effort	Always put in 100% effort

In the present study the developed scale had good internal consistency (alpha=.82).

The clinical samples were asked to describe their behaviour before the onset of their illness; the healthy control were asked to describe their behaviour at the present time.

2.2.5.9.2 Attitudes Toward the Illness

Surawy and colleagues (1995) and Wessely and colleagues (1991) have observed that many CFS sufferers have specific illness beliefs and attitudes. These identified beliefs, however, have not been empirically tested or qualitatively explored. Accordingly, the present study included some specific questions to measure the prevalence and strength of these illness convictions.

The clinical samples were asked to indicate on a seven point Likert scale the extent to which they agreed or disagreed with each statement presented. The items addressed their attitude to activity and rest; ability to meet previous standards; the need to strive to achieve those previous standards; being ‘left behind’; perception of laziness if not achieving; the importance of being seen to cope; and the identification of inner strengths through the illness.

2.2.5.9.3 Depressogenic Thinking and Perfectionism

The key factor that the questionnaire was designed to assess was the extent of depressogenic cognitions in the CFS sample. As addressed in the introduction, it has been postulated that cognitive and behavioural therapy may be of benefit to individuals experiencing CFS. Wessely and colleagues (1991; 1994) have proposed that such treatment has its efficacy based in changing maladaptive illness

cognitions; and introducing some control and mastery over the illness through these changed cognitions and the introduction of graded activities. However, previous research, while noting the high association between CFS and depression, has not examined the role of more general and pervasive depressogenic thinking in a possible depressive illness maintenance cycle.

Further, given the suggestions of pre-illness high standards and perfectionism in CFS patients and its known association with depression, it was considered important that the current research incorporate measures of perfectionism to more precisely tap this dimension.

Different measures of depression-associated thinking have been outlined in the introduction. The Dysfunctional Attitude Scale (Weissman and Beck 1978) purports to measure underlying depressogenic thinking and has been found in repeated studies to tap two factors - dependency and high standards, the latter being of particular interest in the present context. It has been found to have good reliability (internal consistency $\alpha=.90$; Oliver and Baumgart 1985); it discriminates depressed from non-depressed samples; has been found to successfully predict relapse (Cane *et al* 1986); and has been found to associate well with changes in depressed state (DeRubeis *et al* 1990).

Accordingly, the DAS (Form A)⁷ was used in the present study. The Scale has 40 items which ask the respondent to indicate on a 7 point Likert scale the extent to which they agree or disagree with the attitudinal statement. Examples of items include "My value as a person depends greatly on what others think of me", "If I fail partly, it is as bad as being a complete failure". These items correspond to the two factors, dependency and high standards, respectively.

In addition, a further 11 items were added to incorporate the factors of perfectionist attitudes identified by Frost and colleagues in their Multidimensional Perfectionism Scale (MPS) - 'concern over mistakes', 'personal standards' and

‘doubt about actions’ (with Cronbach’s alphas of .88, .83 and .77 respectively)(1990). Seven of the relevant items were already included in the DAS⁸. The subscales relating to possible *causation* of perfectionism - parental expectations and parental criticism, were not included as they did not tap underlying attitudes. Similarly, the subscale ‘organisation’ was not included as it was found to measure a different (and positive) construct to the other subscales.

The descriptive work of Surawy and colleagues (1995) found that their sample of CFS patients tended to place great value in ‘emotional strength’, that is, being seen to cope. Another 8 items based on their observations were added and included expressed attitudes such as ‘For me to show emotional distress is a sign of weakness’, ‘People will only value me if I’m coping with stresses’. These items will be considered separately in analysis but were placed with the items of depressogenic thinking and perfectionism as they utilised the same 7 point scale and constituted attitudinal statements. In the current study these items had good internal reliability (alpha=.90).

The total of 19 additional items were randomly inserted to the core of DAS items.

2.2.5.10 Experience Of Counselling

The last section of the questionnaire was included to obtain some quantitative as well as qualitative information about patients’ experience with counselling. Respondents were asked if they had received any counselling regarding their illness; if so, who it was from; and their views on the most helpful approaches. The last was asked in a free format.

⁷ The DAS has two parallel forms - A and B. Most research has used Form A and accordingly Form A was incorporated in the current study.

⁸ The MPS was developed using items from such measures as the DAS.

3. RESULTS

3.1 *QUALITY OF DATA*

Prior to analysis, all data were examined through various SPSS⁹ programs for accuracy of data entry, missing values, and fit between distributions and the assumptions of subsequent multivariate analysis (Tabachnick and Fidell, 1989). The variables were examined separately for the three groups - CFS patients, depressed patients and healthy patients.

All data had legal values. There was little missing data on demographic variables, illness or psychological variables. Given the rarity of missing data, where it occurred group means were allocated in subsequent analyses.

Distributions of variables within each group were checked for normality. Levels of skew and kurtosis were examined and were acceptable ($p < .001$) for all variables with the following exceptions:

- hard driven behaviour in the CFS group where there was a negative skew and positive kurtosis - ie most had led a hard driven lifestyle prior to the illness;
- length of illness in both the CFS and depressed groups where there was both positive skew and positive kurtosis - most had been ill for a shorter time.

In addition, the distributions of variables were checked separately for each group using SPSS histograms and normal distribution plots to check that means and standard deviations were satisfactory and for indications of outliers.

The following outliers were detected ($p < .001$):

⁹ SPSS for Windows Release 7.0 (Dec 19, 1995) was used for all analyses.

- one CFS case where length of illness was 32 years (384 months);
- one depressed case where length of illness was 13 years (156 months); and
- one healthy case with extremely high scores on two of the depressed cognitions measures - DAS Performance and the Frost perfectionist scale - concern over mistakes.

Removal of the CFS outlier restored the distributions on hard driven behaviour and length of illness to a normal distribution in that group.

However, removal of the depressed outlier still left a positive skew on the length of illness distribution in that group. The data were checked for further outliers but no other case met (or were close to) the requirement. Accordingly, another variable was created comprising a transformation of length of illness for use in multivariate analysis. The transformation rendered the distribution normal. For descriptive purposes, the untransformed variable is referred to.

After removal of the univariate outliers, regression runs were conducted on each of the three groups - CFS, depressed and healthy to identify multivariate outliers (Mahalanobis distance with $p < .001$). None were detected.

With the removal of the three univariate outliers, 37 CFS cases, 27 depressed cases and 32 healthy cases remained for analysis.

3.2 APPROPRIATENESS OF SAMPLES

The three samples - CFS, depressed and healthy were compared on key demographic variables to check for comparability using SPSS ANOVA and Crosstabulations. The three samples were comparable in age ($F = .473$, $p = .625$); gender ($\chi^2 = 2.599$, $p = .273$); and marital status ($\chi^2 = 12.080$, $p = .148$). However,

when marital status is dichotomised into married/ not married, the two clinical groups are comparable, but have fewer married subjects than the healthy group ($\chi^2=6.456$, $p=.040$). The latter may be considered a natural correlate of unwell versus healthy groups.

Table 2 Age

		N	Mean	Std. Deviation	Minimum	Maximum
Illness	CFS	37	37.97	10.80	18	60
	Depressed	24	34.83	11.39	19	54
	Healthy	29	36.59	14.70	18	67
	Total	90	36.69	12.26	18	67

Table 3 Gender

			Sex		Total
			Male	Female	
Illness	CFS	Count	6	31	37
		% of Illness	16.2%	83.8%	100.0%
	Depressed	Count	8	18	26
		% of Illness	30.8%	69.2%	100.0%
	Healthy	Count	5	27	32
		% of Illness	15.6%	84.4%	100.0%
Total	Count	19	76	95	
	% of Illness	20.0%	80.0%	100.0%	

Table 4 Marital Status - Married or Unmarried

			not married	married	
Illness	CFS	Count	18	19	37
		% of Illness	48.6%	51.4%	100.0%
	Depressed	Count	15	12	27
		% of Illness	55.6%	44.4%	100.0%
	Healthy	Count	8	24	32
		% of Illness	25.0%	75.0%	100.0%
Total	Count	41	55	96	
	% of Illness	42.7%	57.3%	100.0%	

3.3 DESCRIPTION OF SAMPLES

The two clinical samples were examined to obtain further descriptive information about the nature of the illnesses, and the use of counselling. The clinical groups and the healthy group were also compared on illness symptomatology and on the measures of psychopathology.

3.3.1 LENGTH OF ILLNESS

As noted above, the length of illness of the depressed group is positively skewed. Accordingly, the more appropriate comparison is the median length of illness which is 60 months and 23 months for the CFS and depressed groups, respectively. The most typical length of illness was 12 months for both groups.

Comparison of the transformed scores (transformed to render the distribution normal) indicated that the length of illness was significantly greater in the CFS group ($t=3.652$, $p=.001$). Indeed, the criteria for CFS require a minimum ill period of six months for a diagnosis.

Table 5 Length of Illness (months)

	Valid	Missing	Mean	Median	Mode	Std. Deviation	Range
CFS	36	1	72.67	60.50	12	52.17	6-182
Depressed	24	3	33.21	23.00	12	30.59	2-128

3.3.2 STAGE OF ILLNESS

Clinical subjects were asked to indicate if they thought their illness was in its beginning stage, in its midst, in the recovery stage or not known. The most common category indicated in the CFS group was ‘midst’, while the depressed group more typically thought they were in ‘recovery’. The pattern of responses differed between the two groups primarily because of the large number of ‘don’t know’ responses in the CFS group ($\chi^2=9.150$, $p=.027$). If the ‘don’t know’ responses are treated as missing data, the frequency of identified stage of illness is more comparable between the two groups ($\chi^2=5.706$, $p=.058$).

Table 6 Identified Stage of Illness

			Stage of Illness				Total
			beginning	midst	recovery	don't know	
ILLNESS	1	Count	0	14	10	13	37
		% of ILLNESS	.0%	37.8%	27.0%	35.1%	100.0%
	2	Count	3	7	13	4	27
		% of ILLNESS	11.1%	25.9%	48.1%	14.8%	100.0%
Total		Count	3	21	23	17	64
		% of ILLNESS	4.7%	32.8%	35.9%	26.6%	100.0%

3.3.3 SYMPTOMATOLOGY

Subjects were asked to indicate the severity of symptoms experienced from a list incorporating all of the criteria of both CFS and depression. Four variables were constructed from the data. One variable was created to indicate the number of

symptoms that were rated as occurring frequently or everyday. Another summed the severity of the symptoms. One variable specifically indicated the severity of the depression criteria and another of the CFS criteria.

The two clinical groups had comparable levels of frequency of occurrence of overall symptomatology (Bonferroni test¹⁰; $p=.550$) as well as severity of symptoms ($p=.598$). As expected, the healthy group had lower levels of symptomatology ($p<.001$).

While the two clinical groups had similar levels of symptoms relating to depressed criteria (Bonferroni test $p=.567$), the CFS group had a higher level of symptoms relating to CFS criteria ($p=.005$). Again, as expected, the healthy group had a lower incidence of both CFS and depressed criteria ($p<.001$).

Table 7 Illness Symptoms

			N	Mean	Std. Deviation	Minimum	Maximum
Total Symptoms	Illness	CFS	37	41.2432	12.8396	4.00	65.00
		Depressed	27	37.0741	17.3003	9.00	69.00
		Healthy	32	10.6250	6.6805	.00	26.00
		Total	96	29.8646	18.6771	.00	69.00
Symptom Frequency	Illness	CFS	37	13.7297	5.6894	.00	23.00
		Depressed	27	11.8889	7.5362	.00	24.00
		Healthy	32	1.2813	1.7457	.00	5.00
		Total	96	9.0625	7.7430	.00	24.00
Depression Symptoms	Illness	CFS	37	15.8649	5.8933	.00	28.00
		Depressed	27	17.9259	8.4075	4.00	32.00
		Healthy	32	4.4375	3.7411	.00	14.00
		Total	96	12.6354	8.4693	.00	32.00
CFS Symptoms	Illness	CFS	37	18.9189	5.8328	3.00	28.00
		Depressed	27	14.6296	6.2827	2.00	27.00
		Healthy	32	5.7500	2.9403	.00	10.00
		Total	96	13.3229	7.6496	.00	28.00

Below is a list of the symptoms rated by the clinical subjects as occurring frequently or everyday. The healthy subjects rated many of the symptoms as only

¹⁰ Bonferroni tests were used following significant ANOVAs to provide Type I protection for *a posteriori* multiple comparisons.

occurring infrequently if at all. The most rated symptoms by the healthy subjects were the items irritability and inability to sleep which were rated by 16% of those subjects as occurring frequently or everyday.

Table 8 Symptoms Reported by Clinical Samples¹

Symptom	CFS Group %	Depressed Group %
Muscle weakness	65	30
Muscle pain	76	44
Fatigue after exercise	62	41
Tired	89	82
Slowed down	84	70
Agitation	68	56
Chills or mild fever	41	22
Sore throat	49	19
Swollen glands	30	15
Headaches	65	30
Joint pains	62	44
Irritation by light	38	26
Blurred or double vision	24	26
Forgetfulness	68	56
Irritability	65	59
Confusion	60	41
Inability to think clearly	70	59
Inability to concentrate	70	52
Depressed mood	38	70
Feeling worthless	30	59
General feelings of guilt	24	59
Feeling the future is bleak	30	56
Recurrent thoughts of death	0	0
Lack of interest or pleasure in most activities	38	63
Inability to sleep	51	56
Sleeping too much	38	15
Reduced appetite	16	26
Other	24	15

¹ Symptoms rated as occurring frequently or everyday (those rated by more than half of the respondents as occurring frequently or everyday are in bold).

3.3.4 FUNCTIONAL IMPAIRMENT

The clinical subjects indicated on a nine point scale the degree of functional impairment caused by their illness. Five separate areas of functioning were addressed. The CFS group and the depressed group had comparable levels of functional impairment overall ($t=1.329$, $p=.189$) and in four of the five specific areas - ability to work ($t=1.453$, $p=.151$); self-care ($t=.316$, $p=.753$); social leisure ($t=1.024$, $p=.310$); and private leisure ($t=1.148$, $p=.256$). The CFS group reported a slightly greater level of functional impairment in family/home management - about half a point on the 9 point scale ($t=2.024$, $p=.047$).

3.3.5 PSYCHOPATHOLOGY

The Hospital Anxiety and Depression Scale (HADS) provides separate scores for depression and anxiety and provides cutoffs for severity. The two clinical groups had comparable levels of depression (Bonferroni test, $p=.088$) and anxiety (Bonferroni test $p=.214$) and greater levels of psychopathology than the healthy subjects ($p<.001$).

Table 9 Psychopathology

			N	Mean	Std. Deviation	Minimum	Maximum
HADS-Anxiety Score	Illness	CFS	37	10.4595	4.5129	1.00	21.00
		Depressed	27	12.5926	6.1222	1.00	21.00
		Healthy	32	5.0000	2.9838	.00	11.00
		Total	96	9.2396	5.5417	.00	21.00
HADS-Depression Score	Illness	CFS	37	8.0270	3.7378	2.00	19.00
		Depressed	26	10.1538	4.9209	2.00	21.00
		Healthy	32	2.5313	2.4493	.00	10.00
		Total	95	6.7579	4.8657	.00	21.00

The clinical groups had comparable numbers of subjects with different levels of severity depression ($\chi^2=6.785$, $p=.079$) and anxiety ($\chi^2=6.107$, $p=.107$).

Table 10 HADS Depression Categories

			HADS-depression category				Total
			normal	mild	moderate	severe	
Illness	CFS	Count	20	8	8	1	37
		% of Illness	54.1%	21.6%	21.6%	2.7%	100.0%
	Depressed	Count	8	4	10	4	26
		% of Illness	30.8%	15.4%	38.5%	15.4%	100.0%
Total		Count	28	12	18	5	63
		% of Illness	44.4%	19.0%	28.6%	7.9%	100.0%

Table 11 HADS Anxiety Categories

			HADS-anx category				Total
			normal	mild	moderate	severe	
Illness	CFS	Count	11	5	15	6	37
		% of Illness	29.7%	13.5%	40.5%	16.2%	100.0%
	Depressed	Count	8	1	7	11	27
		% of Illness	29.6%	3.7%	25.9%	40.7%	100.0%
Total		Count	19	6	22	17	64
		% of Illness	29.7%	9.4%	34.4%	26.6%	100.0%

However, if the categories are collapsed into two - normal and mild combined; and moderate and severe combined, the depressed group has a significantly greater number of subjects with moderate and severe levels of depression than the CFS group ($\chi^2=5.741$, $p=.017$). The levels of anxiety when dichotomised, are however, equally elevated in the two clinical groups ($\chi^2=.644$, $p=.422$).

Table 12 HADS Depression Categories Collapsed

			HADS-Depression Category		Total
			normal/mild	moderate/severe	
Illness	CFS	Count	28	9	37
		% of Illness	75.7%	24.3%	100.0%
	Depressed	Count	12	14	26
		% of Illness	46.2%	53.8%	100.0%
Total		Count	40	23	63
		% of Illness	63.5%	36.5%	100.0%

Table 13 HADS Anxiety Categories Collapsed

			HADS-Anxiety Category		Total
			normal/mild	moderate/severe	
Illness	CFS	Count	16	21	37
		% of Illness	43.2%	56.8%	100.0%
	Depressed	Count	9	18	27
		% of Illness	33.3%	66.7%	100.0%
Total		Count	25	39	64
		% of Illness	39.1%	60.9%	100.0%

Some 46% of the CFS group and 69% of the depressed group had at least a mild level of depression on the scale. Twenty four percent of the CFS group and 54% of the depressed group had a moderate or severe level of depression.

When the item relating to “I feel as if I am slowed down” is removed (the only item relating to physical symptoms of depression), 38% of the CFS group and 69% of the depressed group have at least mild levels of depression. Eleven percent of the CFS group and 42% of the depressed group have moderate or severe levels of depression on this abbreviated scale.

Some 57% of the CFS group and 67% of the depressed group had clinical levels of anxiety.

3.3.6 PERCEIVED CRITICISM AND SUPPORT

The two clinical groups were asked to indicate on a five point scale how critical and how supportive key people (partners, mothers, fathers, children, families, friends, colleagues, doctors, acquaintances and themselves) had been to them in their illness. These levels were comparable between the two groups for key individuals (p values all $>.131$) and overall ($p=.918$).

Interestingly, both the CFS and depressed groups rated themselves as more self-critical during the worst time of their illness than other significant people (CFS group $t=-8.859$, $p<.001$; depressed group $t=-6.732$, $p<.001$).

3.3.7 PREFERRED COUNSELLING APPROACHES

At Attachment 2 is a list of the counselling approaches found helpful by the CFS and depressed subjects. A broad range of counselling and therapeutic approaches were listed ranging from validation of the illness as an organic disease to learning to reduce self-expectations, relaxation, pain management and family counselling.

3.4 SPECIFIC HYPOTHESES

The following results relate to the specific hypotheses of this research.

3.4.1 LEVELS OF ACHIEVEMENT (HYPOTHESIS 1)

3.4.1.1 Educational, occupational and sporting achievement

It was hypothesised that the CFS group would have achieved at higher levels in their education, occupation and in sport (1a)).

The CFS group had a higher level of education than the depressed group ($t=2.293$, $p=.025$) and the healthy group ($t=1.912$, $p=.060$); the depressed and healthy groups did not differ ($t=.346$, $p=.731$). Fifty one percent of the CFS group, 22% of the depressed group and 31% of the healthy group had a bachelor's degree or higher qualification.

Table 14 Educational Qualifications

Illness	Not Applic- able		Basic Vocation- al. Cert.		Skilled Vocation- al Cert.		Assoc. Diploma		Under- grad. Diploma		Bachelor Degree		Post- grad. Degree		Higher Degree	
	%	(N)	%	(N)	%	(N)	%	(N)	%	(N)	%	(N)	%	(N)	%	(N)
CFS	24	(9)	8	(3)	5	(2)	8	(3)	3	(1)	27	(10)	11	(4)	14	(5)
Depre- ssion	37	(10)	15	(4)	11	(3)	7	(2)	7	(2)	19	(5)	0	(0)	4	(1)
Healthy	44	(14)	6	(2)	9	(3)	3	(1)	3	(1)	13	(4)	19	(6)	0	(0)

The three groups attained similar levels in their occupations ($F=.906$, $p=.408$).

The most common occupations were clerical or professional, or involved doing unpaid work. It should be noted, however, that none of the CFS group had a ‘blue collar’ job, while 18% of the depressed group and 6 % of the healthy group did.

Table 15 Occupation

Occupation	Illness					
	CFS		Depression		Healthy	
	%	N	%	N	%	N
Unpaid	5	2	4	1	19	6
Labourer	0	0	4	1	3	1
Driver	0	0	7	2	0	0
Sales	11	4	11	3	3	1
Clerk	24	9	26	7	25	8
Trades	0	0	7	2	3	1
Para-Professional	11	4	4	1	3	1
Professional	27	10	26	7	25	8
Manager	16	6	11	3	16	5
Missing	5	2	0	0	3	1

The three groups had similar levels of participation in sport at a highly competitive level, that is at State or National level - about 23% of each group participated ($\chi^2=.193$, $p=.908$).

3.4.1.2 Achievement Relative to Parents

Consistent with the view that those with CFS tend to be high achievers, it was hypothesised (1b)) that patients with CFS would have made greater educational and occupational gains relative to their parents than the other two groups.

However, there were no significant differences amongst the three samples in the gain in education ($F=.544$, $p=.583$) or occupational level ($F=2.037$, $p=.136$), or in a composite of these factors ($F=1.541$, $p=.221$). In each sample there was an overall gain in education and occupational level relative to the subjects' parents.

3.4.1.3 Pre-illness Achievement-oriented Behaviour

One measure of the questionnaire involved the two clinical samples in indicating their 'hard-driven' behaviour prior to the illness. The healthy group was asked to indicate their current level of this behaviour. It was hypothesised that the CFS group, at least perceived that they had a higher level of this particular aspect of achievement-oriented behaviour than the other groups (1c)). The results supported this hypothesis with the CFS group recalling a higher level of hard-driven behaviour than the depressed group ($t=2.664$, $p=.011$) and a higher level than the current behaviour in the healthy group ($t=3.117$, $p=.003$).

Table 16 Hard-driven Behaviour

Illness	N	Mean	Std. Deviation
CFS*	35	6.10	0.67
Depression*	27	5.46	1.11
Healthy#	32	5.49	0.93

* Behaviour prior to illness

Current behaviour

3.4.2 DEPRESSOGENIC THINKING OF CFS PATIENTS (HYPOTHESIS 2)

3.4.2.1 Overall Depressogenic Thinking

It was hypothesised that CFS subjects would have higher levels of overall depressogenic thinking than the healthy group, but at a comparable level to the depressed group. The data supported this hypothesis - on the Dysfunctional Attitudes Scale (DAS), the CFS group had a higher level of these depressogenic attitudes than the healthy group ($t=2.910$, $p=.005$) and a comparable level to the depressed group ($t=-1.128$, $p=.264$). The depressed group also had a significantly higher level of these cognitions than the healthy group ($t=3.300$, $p=.003$).

3.4.2.2 Depressogenic Thinking - Performance Evaluation

The central thesis of this study was that CFS subjects would have high levels of depressogenic thinking, and specifically in the factor relating to performance evaluation (2b)). The data support this - the CFS group had higher levels of performance evaluation cognitions than the healthy group ($t=3.861$, $p<.001$) and a comparable level to the depressed group ($t=-1.088$, $p=.281$); the depressed group also had higher levels than the healthy group ($t=4.133$, $p<.001$).

When examining the pattern of differences amongst the groups associated with the ‘approval by others’ factor, while there is a significant difference amongst the groups ($F=4.011$, $p=.021$), there is only a significant difference between the depressed group and the healthy group (Bonferroni test $p=.024$). The mean of the CFS group lies between that of the depressed and healthy groups and is not statistically different from either (depressed group $p=1.000$; healthy group $p=.127$).

Table 17 Depressogenic Thinking - Dysfunctional Attitudes Scale

Illness	N	DAS		DAS - Performance Evaluation		DAS - Approval by Others	
		Mean	Std. Deviation	Mean	Std. Deviation	Mean	Std. Deviation
CFS	37	126.79	33.46	43.28	16.42	39.43	11.34
Depressed	27	138.38	48.79	48.44	21.55	41.89	13.17
Healthy	32	105.90	24.71	30.75	10.19	33.67	10.03

Hypothesis 2c) related to a specific set of performance evaluation and approval of others cognitions eg ‘I need to achieve to be worthwhile’; ‘people will only value me if I’m emotionally strong’ proposed in previous qualitative CFS research (Surawy et al 1995). These hypothesised cognitions were also empirically tested in the current study. It was found that both the CFS group and the depressed groups adhered to the set of cognitions that demand both high standards and gaining the approval of others as was proposed by Surawy. (CFS V’s healthy $t=4.966$, $p<.001$; depressed V’s healthy $t=4.564$, $p<.001$; CFS V’s depressed $t=-.281$, $p=.780$).

Table 18 Depressogenic Thinking - Proposed CFS Cognitions

Illness	N	Proposed CFS Dysfunctional Cognitions (Surawy <i>et al</i>)	
		Mean	Std. Deviation
CFS	37	4.16	1.37
Depressed	27	4.26	1.51
Healthy	32	2.71	1.01

3.4.3 CFS AND PERFECTIONISM (HYPOTHESIS 3)

It was hypothesised (3) that CFS subjects would have high levels of perfectionism. The data indicated that there were higher overall levels of perfectionism in the CFS group compared to the healthy group ($t=3.611$, $p=.001$). Similarly, the depressed group had higher levels of perfectionism than the healthy group ($t=3.775$, $p<.001$). The CFS group and depressed groups had comparable levels ($t=-.377$, $p=.707$).

These differences are maintained in the components of the Frost perfectionism scale that have been found to be associated with psychopathology - the 'concern over mistakes' factor (CFS V's healthy $t=3.321$, $p=.001$; depression V's healthy $t=3.224$, $p=.002$; CFS V's depression $-t=.555$, $p=.581$) and the 'doubts about actions' factor (CFS V's healthy $t=3.806$, $p<.001$; depression V's healthy $t=4.762$, $p<.001$; CFS V's depression $t=-.687$, $p=.495$). However, there are no differences amongst the groups on the aspect of perfectionism not associated with psychopathology - 'setting standards' ($F=.891$, $p=.414$).

Table 19 Perfectionism - Frost Scale (mean ratings)

Illness	N	Frost Overall		Frost - Concern over Mistakes		Frost - Doubts About Actions		Frost - Setting Standards	
		Mean	Std. Deviation	Mean	Std. Deviation	Mean	Std. Deviation	Mean	Std. Deviation
CFS	37	3.86	1.14	3.38	1.28	3.85	1.60	4.71	1.42
Depression	27	3.96	1.14	3.58	1.52	4.11	1.34	4.55	1.12
Healthy	32	3.01	0.81	2.50	0.92	2.63	1.06	4.32	1.04

3.4.4 ASSOCIATION BETWEEN SEVERITY OF ILLNESS, AND DEPRESSION AND DEPRESSED THINKING (HYPOTHESIS 4)

3.4.4.1 Association Between Severity of Illness and Measures of Psychopathology

It was predicted that severity of symptoms would be positively associated with depression (4a)). While no prediction was made regarding the relationship with anxiety, also measured by the Hospital Anxiety and Depression Scale (HADS), its relationship with the symptoms was also explored. The following matrix of results emerged:

Table 20 Association Between Symptoms and Psychopathology

Illness	N	Symptoms	HADS - Depression		HADS - Anxiety	
			r	p (1 tailed)	r	p (2 tailed)
CFS	37	CFS Criteria	.25	.068	.24	.153
		Total Symptoms	.37*	.011	.41*	.013
Depression	26	CFS Criteria	.68***	<.001	.73***	<.001
		Total Symptoms	.79***	<.001	.81***	<.001
Healthy	32	CFS Criteria	.29	.055	.25	.161
		Total Symptoms	.54**	.001	.49**	.005
Total	95	CFS Criteria	.63***	<.001	.60***	<.001
		Total Symptoms	.75***	<.001	.73***	<.001

* p<.05 ** p<.01 ***p<.001

There was a strong relationship between the total symptom list (which incorporated all of the reported CFS symptoms, as well as the symptoms for depression) and depression in all groups and in the total study sample ($p \leq .011$). However, the specific CFS symptoms associated strongly with depression in only the depressed sample and in the total sample ($p < .001$); for the CFS group and the healthy group, the association was weaker and only approached significance (CFS $r = .25$, $p = .068$; depressed $r = .29$, $p = .055$).

An identical pattern emerged in relation to anxiety as measured on the HADS.

3.4.4.2 Association Between Severity of Illness and Depressogenic Thinking

It was also hypothesised that severity of illness would be positively associated with depressogenic thinking patterns (4b)). The results were mixed with total symptoms being associated with depressogenic thinking as measured by the DAS for the total group ($p < .001$), the CFS group ($p = .012$) and the depressed group ($p < .001$), but not the healthy group ($p = .325$).

The specific CFS symptoms correlated with DAS scores for the total group ($p < .001$) and the depressed group ($p = .004$); the association within the CFS group was weaker and only approached significance ($r = .26$, $p = .059$). There was no association between CFS symptoms and DAS scores for the healthy group ($p = .347$).

Table 21 Association Between Symptoms and Depressogenic Thinking

Illness	N	Symptoms	DAS Score	
			r	p (1 tailed)
CFS	37	CFS Criteria	.26	.059
		Total Symptoms	.37*	.012
Depression	26	CFS Criteria	.50**	.004
		Total Symptoms	.63	<.001
Healthy	32	CFS Criteria	.07	.347
		Total Symptoms	.08	.325
Total	95	CFS Criteria	.42***	<.001
		Total Symptoms	.52***	<.001

* p<.05 ** p<.01 ***p<.001

3.4.5 ASSOCIATION BETWEEN ATTITUDES TO THE ILLNESS, AND
LEVELS OF DEPRESSION AND DEPRESSOGENIC THINKING
(HYPOTHESIS 5)

3.4.5.1 Illness Attribution and Depression

Hypothesis 5a) proposes that an external ie physical attribution of the illness will be associated with higher levels of depression. As can be seen in Table 22, and Table 23, the CFS sample tended to favour a physical attribution for their illness, while the depressed group tended to have a psychological attribution for their illness ($\chi^2=29.967$, $p<.001$).

Table 22 Illness Attribution

			Illness Attribution					Total
			Definitely physical	Physical and some sychological	Equally psysical and sychological	Mainly sychological	Don't know	
Illness	CFS	N	11	17	5		2	35
		% of Illness	31.4%	48.6%	14.3%		5.7%	100.0%
	Depressed	N		7	7	13		27
		% of Illness		25.9%	25.9%	48.1%		100.0%
Total		N	11	24	12	13	2	62
		% of Illness	17.7%	38.7%	19.4%	21.0%	3.2%	100.0%

Table 23 Illness Attribution - Collapsed Categories

			Attribution - Collapsed Categories		Total
			Mainly physical	Psychological significant	
Illness	CFS	Count	28	5	33
		% of Illness	84.8%	15.2%	100.0%
	Depressed	Count	7	20	27
		% of Illness	25.9%	74.1%	100.0%
Total		Count	35	25	60
		% of Illness	58.3%	41.7%	100.0%

The attribution, however, did not relate to severity of depression (overall group $F=1.005$, $p=.413$; CFS group $F=1.050$, $p=.385$; depressed group $F=.266$, $p=.768$) or to anxiety (overall group $F=1.770$, $p=.148$; CFS group $F=2.836$, $p=.054$; depressed group $F=.128$, $p=.880$). Clearly, a physical attribution did not relate to higher levels of depression in the CFS group or the other groups. However, there was a trend in the opposite direction suggesting that an illness attribution that saw psychological factors as significant was associated with higher levels of anxiety in the CFS group ($t=-2.011$, $p=.053$).

3.4.5.2 Illness Attribution and Depressogenic Thinking

Hypothesis 5b) stated that a physical illness attribution would be associated with higher levels of depressogenic thinking. The attribution did not relate to levels of depressogenic thinking in the combined ill group ($F=1.920$, $p=.119$) and in the depressed group ($F=.322$, $p=.727$). For the CFS group, the data in fact suggest that the association is in the other direction ie considering psychological factors as significant (at least equal to physical factors) is associated with higher levels of depressogenic thinking ($F=3.098$, $p=.041$; $r_s=.457$, $p=.004$).

When illness attribution is again dichotomised into ‘mainly physical’ and ‘psychological factors are significant’ the association is simplified. When this is done the CFS group maintains a significant difference indicating that considering psychological factors as significant in the illness is associated with higher levels of depressogenic thinking ($t=-2.592$, $p=.014$). When illness attribution is dichotomised, the trend in the combined illness group is significant, again in the direction of associating higher levels of depressogenic thinking with considering psychological factors as significant ($t=-2.371$, $p=.021$). Again, no significant difference is found in the depressed group ($t=-.810$, $p=.425$).

Table 24 Illness Attribution and Depressogenic Thinking

Illness	Illness Attribution - Collapsed Categories	N	Mean	Std. Deviation	t	p
CFS	Mainly physical	28	120.61	30.60	-2.592*	.014
	Psychological	5	161.00	40.79		
	factors Significant					
Depressed	Mainly physical	7	125.43	46.97	-.810	.425
	Psychological	20	142.91	49.78		
	factors significant					
Total	Mainly physical	35	121.57	33.71	-2.371*	.021
	Psychological	25	146.53	47.89		
	factors significant					

* $p<.05$

3.4.5.3 Illness Beliefs and Depression

The data were explored to determine the association between the CFS illness beliefs outlined in the literature and levels of depression. The beliefs were assessed on a 7 point scale from 1 - ‘totally agree’ to 7- ‘totally disagree’. The CFS group and the depressed group adhered to the overall set of illness beliefs at a comparable level ($t=-1.490$, $p=.141$). The mean rating indicated slight overall agreement - a mean rating of 3.297 in the CFS group and 3.577 in the depressed group (3 - ‘agree slightly’; 4 - ‘neutral’).

Interestingly, the CFSD and depressed group participants had equal median ratings on most of the belief with the exception of the belief ‘ activity makes me feel worse’ ($t=-2.774$, $p=.007$) where the CFS group had a median rating of 2 - ‘agree very much (mean rating of 2.92) and the depressed group had a median rating of 5 - ‘disagree slightly’ (mean rating of 4.26).

Table 25 Adherence to the Illness Beliefs in the Clinical Samples

Illness Belief	CFS		Depressed	
	N	Median	N	Median
Activity makes me feel worse	37	2	27	5
I can do things to the same standard as I used to	37	6	26	5
I should strive to achieve my previous level of performance and activity	37	3	27	3
Because of my illness I feel that I am being left behind	37	2	27	3
I feel that it is important to be seen to cope	37	2	27	2
I should rest as much as possible to get better	37	3	27	3
People think I’m lazy if I don’t achieve as much as I used to	37	3	27	3

In the combined ill group, levels of depression (categorised as normal, mild, moderate or severe) did not vary according to illness beliefs ($F=1.544$, $p=.213$), nor did they in the CFS sample ($F=.573$, $p=.637$) or the depressed group ($F=3.141$, $p=.047$, Bonferroni tests $p>.067$). The trend does, however, when correlational data are looked at, suggest that strongly adhering to the set of illness beliefs is associated with higher levels of depression. The correlations found are summarised in Table 26 below.

The association between illness beliefs and levels of anxiety was also explored and yielded the same pattern of results as with levels of depression (combined ill group $F=1.671$, $p=.183$; CFS group $F=1.314$, $p=.286$; depressed group $F=1.339$, $p=.287$). Again, the correlational data suggested a trend associating adhering to the illness beliefs and higher levels of anxiety.

Table 26 Correlations Between Illness Beliefs and Psychopatholgy

Psychopathology	Illness	N	r	p
HADS - <u>Depression</u>	CFS	37	-.275*	.050
	Depressed	26	-.343*	.047
	Total	63	-.248*	.026
HADS - <u>Anxiety</u>	CFS	37	-.271	.053
	Depressed	26	-.334*	.048
	Total	63	-.247*	.025

* $p<.05$

3.4.5.4 Illness Beliefs and Depressogenic Thinking

The data were examined also to determine whether the relationship between adhering to the set of illness beliefs and levels of depressogenic thinking. T-tests were conducted for each clinical group and in the combined clinical groups combined to determine if there was a difference between illness beliefs and high or low DAS - depressogenic thinking scores. No differences were found (combined group $t=1.693$, $p=.096$; CFS group $t=1.813$, $p=.078$; depressed group $t=1.001$, $p=.327$), although weak correlations between DAS scores and illness belief scores

were observed - all in the negative direction indicating a weak link between holding the illness beliefs and higher levels of depressogenic thinking. These are summarised in Table 27.

Table 27 Correlations Between Illness Beliefs and Depressogenic Thinking (DAS Scores)

Illness	N	r	p
CFS	37	-.304*	.034
Depressed	26	-.289	.076
Total	63	-.253*	.023

*p<.05

No associations were found between ratings on the ‘activity makes me feel worse’ item and either depression, anxiety or depressogenic thinking scores in the CFS group ($p>.164$). However, in the depressed group there was a moderate association with the measures of psychopathology (HADS - Depression - $r=-.429$, $p=.014$; HADS - Anxiety - $r=-.422$, $p=.014$; DAS - $r=-.276$, $p=.082$).

3.5 EXPLORATORY ANALYSIS

The following analyses were conducted to provide further information from the available data.

3.5.1 ILLNESS BELIEFS AND FUNCTIONAL IMPAIRMENT

The data were examined to see if the set of illness beliefs was associated with functional impairment. There was no association in the combined clinical group ($r=-.188$, $p=.072$), the CFS group ($r=-.070$, $p=.343$) or the depressed group ($r=-.260$, $p=.099$). However, when the item ‘activity makes me feel worse’ was examined, there was a moderate association - adhering to that belief was associated with greater functional impairment in both the clinical groups (CFS - $r=-.476$, $p=.002$; depressed - $r=-.561$, $p=.001$).

3.5.2 ASSOCIATION BETWEEN STAGE OF ILLNESS AND DEPRESSION

The data were explored to determine whether there was a relationship between stage of illness and levels of depression; it may be expected that perceiving oneself as being in a recovery phase may be associated with lower levels of depression. It was found that the level of depression did not differ significantly between subgroups on the basis of stage of illness; in the depressed group, a trend suggesting that being in the recovery group is associated with lower levels of depression than being in the midst of the illness is found ($F=2.868$, $p=.060$; Bonferroni test $p=.066$). The small sub-sample sizes should be noted.

Table 28 Perceived Stage of Illness and Depression

Illness		Perceived Stage of Illness				F	p
		Beginning	Midst	Recovery	Don't Know		
CFS	Mean Std. Dev. N	0	7.64 3.18 14	6.50 3.90 10	9.62 3.84 13	2.224	.124
Depressed	Mean Std. Dev. N	12.33 2.89 3	14.17 4.00 6	8.08 4.50 13	9.25 5.68 4	2.868	.060
Total	Mean Std. Dev. N	12.33 2.89 3	9.60 4.52 20	7.39 4.23 23	9.53 4.14 17	1.910	.138

Any relationship between stage of illness and levels of anxiety was also explored and yielded the same pattern of results as in the case of depression:

Table 29 Perceived Stage of Illness and Anxiety

Illness		Perceived Stage of Illness				F	p
		Beginning	Midst	Recovery	Don't Know		
CFS	Mean Std. Dev. N	0	8.56 5.11 14	10.40 4.06 10	12.23 3.75 13	1.988	.153
Depressed	Mean Std. Dev. N	14.67 8.39 3	16.57 4.28 7	9.62 5.32 13	13.75 6.85 4	2.565	.079
Total	Mean Std. Dev. N	14.67 8.39 3	11.43 6.03 21	9.96 4.72 23	12.59 4.44 17	1.240	.303

3.5.3 PREDICTING GROUP MEMBERSHIP

A direct discriminant function analysis was conducted to determine which factors best predicted group membership in the clinical samples. Three demographic variables - age, sex and marital status; 4 illness variables - CFS symptoms, depression symptoms, length of illness and functional impairment; 2 measures of psychopathology - depression (HADS-D) and anxiety (HADS-A); and 3 attitudinal variables - illness attribution, depressogenic thinking (DAS) and illness beliefs were entered as possible group predictors.

Of the 64 clinical subjects, 11 were excluded from analysis because of missing data. Missing data appeared to be randomly scattered throughout groups and predictors. The data had been previously checked for outliers and met the requirements of multivariate analysis.

The discriminant function yielded a $\chi^2(12) = 30.848$, $p = .0021$. The loading matrix of correlations between predictors and the discriminant function, as seen in Table 30, suggests that the best predictor is illness attribution. The CFS group tend to hold an external illness attribution (85%) while the depressed group tend

to have a psychological attribution (74%). Other predictors had loadings less than .50 (Tabachnik and Fidell 1989, p 572).

Table 30 Results of Direct Discriminant Function Analysis

Predictor Variable	Correlations of Predictor Variables With Discriminant Function
Illness attribution	.59
Anxiety (HADS-A)	.47
Length of illness	-.44
Depression (HADS-D)	.43
CFS symptoms	-.31
DAS (Depressogenic thinking)	.25
Depression symptoms	.25
Age	-.11
Functional Impairment	-.09
Sex	-.08
Marital status	-.06
Illness beliefs	.05
Statistics	
Canonical R	.70
Eigenvalue	.98
Wilks' Lambda	.50
Chi-square(12)	30.84, (p=.0021)

The discriminant function classified 55 (86%) of all clinical cases correctly. This compares with a correct classification rate of 34 (53%) by chance alone. The classification results summarised in Table 30 indicate that most of the CFS subjects were correctly classified, but 26% of the depressed sample were incorrectly classified as being in the CFS sample (Note that 26% of the depressed sample had a predominately physical illness attribution).

Table 31 Direct Discriminant Function Classification Results

Actual Group	N	Predicted Group Membership	
		CFS	Depressed
CFS	37	35 94.6%	2 5.4%
Depressed	27	7 25.9%	20 74.1%
Percent correctly classified	86%		

A stepwise discriminant function analysis incorporating the same predictor variables was conducted to determine which combination of the variables had the greatest ability to discriminate between the two clinical groups. The Wilks' lambda minimisation method was used, with a minimum tolerance level of .001, a maximum significance of F to enter of .05 and a minimum significance of F to remove of .10 (Tabachnik and Fidell 1989, p 535; Norusis 1988, p 93).

Only one variable (one step) was entered in the analysis - illness attribution. This provided a canonical correlation of .503 (Wilks' lambda=.747; $\chi^2=14.750$; $p=.0001$). No further variables accounted for sufficient variance to be entered after illness attribution was included.

With the function arising from the stepwise discriminant analysis, 50 (78%) of all clinical cases were correctly classified. Again, this compares to a correct classification by chance alone of 34 (53%). The classification results summarised in Table 32 indicate that, as with the direct analysis, most of the CFS subjects were correctly classified, but 26% of the depressed sample were incorrectly classified as being in the CFS sample. Hence, the slightly better classification results achieved when all 12 variables are included in the function (ie direct method), is associated with a better classification of the CFS subjects, but does not improve the correct classification of the depressed subjects.

Table 32 Stepwise Discriminant Function Classification Results - Prediction with Illness Attribution

Actual Group	N	Predicted Group Membership	
		CFS	Depressed
CFS	37	30 81.1%	7 18.9%
Depressed	27	7 25.9%	20 74.1%
Percent correctly classified	78%		

When illness attribution is excluded from the analysis, 3 variables - CFS criteria, depression criteria and HADS - Anxiety are entered in that order. This solution provides a canonical correlational of .658 (Wilk's lambda=.567; $\chi^2=29.237$, $p<.00001$). With the function arising from this stepwise discriminant analysis 52 (81%) of all clinical cases were correctly classified. This is a significant improvement over the chance rate (53%). It provides the following classification results:

Table 33 Stepwise Discriminant Function Classification Results - Prediction with CFS Criteria, Depression Criteria and HADS - Anxiety (Illness Attribution Excluded)

Actual Group	N	Predicted Group Membership	
		CFS	Depressed
CFS	37	34 91.9%	3 8.1%
Depressed	27	9 33.3%	18 66.7%
Percent correctly classified	81%		

When discriminant function analysis is applied to all three groups, a two variable solution is obtained in a stepwise procedure - CFS criteria and depression criteria. This resulted in a canonical correlation of .744 for the first function and .541 for the second. It provides the following classification rate:

Table 34 Stepwise Discriminant Function Classification Results - Prediction with CFS Criteria and Depression Criteria (all groups)

Actual Group	N	Predicted Group Membership		
		CFS	Depressed	Healthy
CFS	37	30 81.1%	2 5.4%	5 13.5%
Depressed	27	7 25.9%	14 51.9%	6 22.2%
Healthy	32	0 .0%	2 6.3%	30 93.8%
Percent correctly classified	77%			

4. DISCUSSION

The current research aimed to determine whether particular depressogenic cognitions were instrumental in maintaining depression in CFS. It was postulated specifically that a thinking style which emphasised meeting very high standards and perfectionistic tendencies would be associated with the illness. This was based on the suggestion in the literature that those with CFS had tended to be high achievers and performance driven prior to the illness.

While there are some caveats on the information obtained relating to the sample size and the difficulties inherent in a questionnaire design, a wealth of information was provided in the study. The data provided some of the first information about CFS patients in the primary care context - where the majority of CFS sufferers are encountered “the real chronic fatigue syndrome expertise remains at the ‘coalface’. It is the GPs who provide the information, support, diagnosis, treatment and care for the vast majority of sufferers.” (Shaw, 1996).

This discussion will comprise five main sections - the first will examine the characteristics of the sample, and where possible, will compare those characteristics with the available information provided by other research; secondly, the specific hypotheses tested will be reviewed and related to the literature; thirdly, the limitations of the study will be examined; fourthly, the clinical implications of the findings will be canvassed; and finally, suggestions for future research will be made.

4.1 CHARACTERISTICS OF THE SAMPLE

4.1.1 DEMOGRAPHIC VARIABLES

The CFS sample had a mean age of 38 years and were predominantly female - some 84%. This is consistent with the demographics reported in other studies

(Wilson *et al*, 1994; Powell *et al* 1990; Blakely *et al* 1991). Few studies report marital status or educational level. Just over half of the CFS sample were married/de facto and 51% of the CFS sample had a bachelor's degree or higher qualification. Ray *et al* (1993) note that typically CFS samples are highly educated and indicate a mean of 14 years of education in their sample (indicating a significant number had a bachelor's degree or higher qualification). The latter finding provides some support to the suggestion that those with CFS have achieved at a higher level - this is discussed more fully when the hypotheses are discussed below.

In the present study the CFS sample was also comparable to the control groups - depressed and healthy patients, in age and gender. Seventy-five percent of the healthy group were married/de facto while about half of the two clinical groups - CFS and depressed were in a relationship. The lower relationship rate in the clinical groups could be considered a natural correlate of the illnesses.

There is a paucity of information about the occupational status of CFS patients, so comparison is not possible.

4.1.2 ILLNESS CHARACTERISTICS

In the current study, the median length of illness of CFS was 60 months. This contrasts with a median duration of 30 months in the Lloyd and co-workers primary care, rural based prevalence study (1990). They report a range of 6 months to 25 years. A similar range was found in the present study - 6 months to 32 years¹¹. The majority of studies have been conducted on patients in tertiary care settings and accordingly, typically report longer illness duration - for example, a *mean* of 110 months is reported in Wilson's and colleagues' study (1994).

¹¹ This case was, however, excluded as an outlier on the basis of the duration of illness.

A greater degree of uncertainty about the illness was reflected in the CFS group than in the depressed sample - 35% of the former and only 15% of the latter did not know what stage of the illness they were at.

4.1.2.1 Symptoms

The symptoms reported by more than half of the CFS group as occurring frequently or everyday included fatigue, muscle weakness, muscle pain, post-exertion fatigue, feeling slowed down, agitation, headaches, joint pains, forgetfulness, irritability, confusion, inability to think clearly, inability to concentrate and inability to sleep. This list overlaps to an extent with the symptoms reported by the depressed patients, with over half of the depressed group reporting frequently or everyday fatigue, feeling slowed down, agitation, forgetfulness, irritability, inability to think clearly, inability to concentrate and inability to sleep in common with the CFS group. Additional frequently reported symptoms in the depressed group include - depressed mood, feeling worthless, general feelings of guilt, feeling the future is bleak and lack of interest/pleasure. The pattern of symptoms indicates a large overlap between the symptoms of the CFS and depressed group with the CFS group having more CFS symptoms, comparable levels of depressed symptoms overall ($p=.567$), but fewer of the anhedonia or affective components of depression.

The symptoms reported in the present study are similar to those found in other studies (Lloyd *et al* 1990; Powell *et al* 1990). Lloyd found that over half of their sample reported the following severe or very frequent symptoms - fatigue, concentration impairment, and disrupted sleep.

4.1.2.2 Functional Impairment

The levels of functional impairment are comparable between the study's two clinical groups and indicate a moderate level of impact of the illnesses - an overall

level of impairment of 4.2 was found. The scale ranged from 0-8, with 0 indicating no impairment and 8 indicating the subject is affected very severely and cannot perform the function. As expected, the level of impairment is less than that reported in studies of tertiary referral samples where subjects are reported as being “severely impaired in all areas of their life” (Powell *et al* 1990, p 667).

Table 35 Functional impairment in CFS samples in different studies

Functional Impairment	Current Study	Butler <i>et al</i> 1991	Ray <i>et al</i> 1993 (component ratings not reported)
Ability to work	5.25	6.31	
Home management	4.53	5.69	
Social leisure activities	4.64	5.72	
Private leisure activities	4.75	5.19	
Self-care	2.06	-	-
Mean overall impairment*	4.79	5.65	5.25

* The mean was calculated in the current study excluding self-care as this component was not included in the overall rating in the other studies.

4.1.2.3 Psychopathology

While most studies have focused on depression as the most prevalent type of psychopathology (Wessely 1991), the current study (along with Ray’s 1993 study) found that anxiety is more common amongst CFS sufferers - 57% had a moderate to severe level of anxiety; only 24% had a moderate to severe level of depression, or only 11%, if the item relating to feeling slowed down is omitted. It should be noted that while levels of psychopathology have been found to be as high as 75% in other studies (Kruesi *et al* 1989; Wood *et al* 1991), these higher levels have been obtained using instruments that include somatic symptoms as components of the diagnostic tool.

Levels of psychopathology were found in the current study to be comparable with those found in studies involving patients from tertiary referral centres and assessed on instruments that excluded somatic symptoms. The Ray *et al* study (1993) which also used the HADS had almost identical anxiety and depression scores to those found in the present study (mean scores - HADS-Anxiety - Ray study 9.61 (SD 4.59), current study 10.46 (SD 4.51); HADS - Depression - Ray study 7.87 (SD 3.78), current study 8.03 (SD 3.74)). The Ray study comprised attendees at a hospital outpatient clinic who had been diagnosed as suffering from CFS.

Similarly, Sharpe and others (1992) reported an incidence of depression *or* anxiety (ie minimal psychiatric caseness), using the HADS as occurring in 66% of their CFS patients. If the one item relating to a somatic symptom - fatigue was removed, the incidence dropped to 56%. In the present study the incidence of a moderate or severe degree of depression *or* anxiety (using the same cutoff as that used in the Sharpe study) was 62% of the CFS sample. If the item relating to fatigue is excluded, it drops to 57%. Interestingly, all of those who had clinical levels of depression when the fatigue item was deleted, also had clinical levels of anxiety.

While functional impairment seems less in the primary care sample, levels of psychopathology are comparable.

4.1.2.4 Social Support

The study canvassed the perceived level of criticism (negative support) and support (positive support) in the clinical samples (Ray 1992). The criticism scale ranged from 'not at all critical' (0) to 'very critical' (3). Key others were rated on average as being 'a little critical', while individuals had themselves been harsher on themselves - a mean rating of just over 'quite critical' (2.16).

Lewis and others (1994) conducted a study in which they looked at the perceived levels of support amongst CFS patients and patients with irritable bowel syndrome (IBS) attending a hospital out-patient clinic. On a scale from 1 'very little support' to 5 'a great deal of support', the CFS group had a mean rating of 2.63 - between a little support and quite supportive. In the current study, CFS patients indicated on a scale from 'completely unsupportive' (0) to 'very supportive' (3) how supportive they thought key others had been. This resulted in a mean rating of 1.53 - between 'a little supportive' and 'quite supportive' - the same level as that found in the Lewis study. The Lewis study contrasted this perceived level of support in CFS with that perceived amongst IBS patients - the mean rating was 4.36 - between very supportive and a great deal of support. They note the research connecting low perceived social support to immunological changes and depression and suggest that low perceived social support may directly increase vulnerability to CFS (Lewis *et al* 1994). The actual and perceived levels of social support in CFS cases is an area for exploration in therapy.

4.2 THE HYPOTHESES

The individual hypotheses were designed to expand the existing information which indicated a high level of psychopathology amongst CFS patients and to provide some more specific data on which to guide therapeutic treatment of CFS sufferers. It was proposed that CFS patients would have a high level of depressogenic thinking - particularly in the area of rigidly setting high standards. Beck (1976, 1979) describes such thinking as being associated with rejecting help, pessimism about recovery and a great concern about not being able to perform and meet the individual's usual high standards.

In short, the study aimed to determine if CFS patients tended to this depressogenic thinking pattern, and secondly, to determine if there was a material basis associated with this harsh and self-critical thinking - indications of a high

level of pre-illness achievements, indications of hard-driven pre-illness behaviour, and a striving and achieving approach to the illness.

The correlates of having an external ie physical illness attribution was also examined, following the suggestions in previous studies that an external illness attribution is associated with more negative illness outcomes (Butler et al 1991; Sharpe et al 1992).

4.2.1 LEVELS OF ACHIEVEMENT (HYPOTHESIS 1)

4.2.1.1 Educational, Occupational and Sporting Achievement

Some gross indicators of achievement were examined, as it was hypothesised that patients with CFS would have been high achievers in their pre-illness days. This was based on much conjecture in the literature and little testing out of the suggestion. However, most studies have reported that CFS sufferers tend to be well educated (Shafran 1991; Woodward 1993) and a high incidence of CFS has been reported amongst elite athletes (Puffer and McShane 1991). By contrast, however, Lloyd found in a rural prevalence study that the social status of the CFS group matched the base population (Lloyd *et al* 1990).

In the current study, the educational level, occupation and participation in high level sporting endeavours were canvassed.

Fifty-one percent of the CFS group had a bachelor's degree or higher qualification. This contrasts with 22% in the ACT population (ABS 1994, Cat No. 6235.0, Table 16). In Woodward's study of an ACT sample of CFS sufferers, 76% were tertiary trained (it is unclear whether they completed their studies); as noted above, in Ray's 1993 study she found a mean of 14 years of education - indicating that a significant proportion had tertiary level qualifications. In the present study, the CFS group had a significantly greater number of tertiary

qualifications at the degree level or higher than the depressed group - 22%, the healthy group - 31%, or the population - 22%.

There does seem to be some *prima facie* evidence that CFS sufferers have been high achievers in the educational sphere. However, it could equally be that they come from families of higher socio-economic status - accordingly, it is necessary to determine whether they achieved relative to their parents at a higher rate than their peers.

In terms of occupational achievement, the three study groups attained similar levels overall ($F=.906, p=.408$). However, when occupations are categorised as 'unpaid', 'blue collar', 'white collar' and 'professional/management', the percentages are:

Table 36 Occupational Groupings of Study Samples

	Unpaid %	'Blue Collar' %	'White Collar' %	Professional/ Management %
CFS*	5	0	35	54
Depressed*	4	18	37	43
Healthy*	19	6	28	42

* Note that percentages do not necessarily add to 100% because of missing data and rounding .

As can be seen, the CFS group is over represented in the white collar/professional groupings. Again, to determine whether the higher occupational status of the CFS subjects is based on their levels of achievement or because they come from families of higher socio-economic status is unclear unless they have made occupational gains relative to their parents and at a greater level than their peers.

As a high incidence of CFS has been reported in elite athletes (Puffer and McShane 1991), participation in sport at a highly competitive level (State or national level) was canvassed. Twenty-two percent of the CFS group had participated at this level. This appears to be a high level, but was comparable to

the level of participation in the depressed group (26%) and the healthy group (22%). Given that 23% of Australian females¹² participate in sport as a player at any level (ABS 1993. Cat No. 6285.0, Table 3, p7), the reported levels participating at State or National levels appear high. The figures in the study may be inflated because the respondents did not discern the level nominated. Alternatively, the figures are accurate but appear high as the question asks about participation over a lifetime, not current participation.

4.2.1.2 Achievement Relative to Parents

Contrary to prediction, the CFS group had not made greater gains in education and occupation relative to their parents than the depressed or healthy groups. This negative finding could be interpreted in one of two ways - either that CFS patients have tended to come from more middle class backgrounds, or that the measures used in the study were too gross to discriminate achievement gains. Probably a combination of both is correct.

However, overall there is some support for the contention that CFS sufferers have been high achievers - they have become highly educated with the majority having tertiary qualifications; they have tended to attain professional positions; and have (along with the subjects in the study's control groups) had a high participation in competitive sport.

4.2.1.3 Pre-illness Achievement-oriented Behaviour

A coping style of 'pushing through' has been described of CFS sufferers (Woodward 1993). While Lewis and colleagues (1994) found little basis for a Type A behaviour tendency in CFS patients, they did find a suggestion of 'hard-driving behaviour' in their sample. In considering achievement orientation, a

¹² Females were chosen for comparison as the majority of each study sample were female.

measure of this pre-illness hard-driven behaviour was constructed from components of the Bortner Scale (1969).

The findings of the current study supported this hypothesis - the CFS sample had at least a higher perception of pre-illness hard-driven behaviour than their depressed counterparts or of the reported current behaviour¹³ of the healthy group. The CFS group rated the items on a seven point scale as being less than one point off the most extreme ratings eg “would go ‘all out’ to get things done”, “always put in 100% effort”.

While the findings are suggestive of a self-induced, pressurised lifestyle for CFS sufferers prior to their illness, it is possible that the higher reported ‘hard-driving’ behaviours are an artefact of altered perceptions of earlier behaviours (Lewis et al 1994). However, if that were the case, it would not explain the lower ratings of pre-illness hard-driving behaviours amongst the depressed sample. Again, there is some further indications of a pre-illness achievement-oriented profile amongst CFS sufferers. In Woodward’s words “individuals who have developed this illness [CFS] have characteristics in common. They have been active, productive and conscientious people.” (1993, p2).

4.2.2 DEPRESSOGENIC THINKING OF CFS PATIENTS AND PERFECTIONISM (HYPOTHESIS 2 AND 3)

The central thesis of this study is that if those with CFS have been high achievers and then succumb to a viral or otherwise caused illness which prevents them from being active and achieving, then those very high standards and previously positive and egosyntonic perfectionist tendencies may lead to a vicious cycle of depression and/or anxiety. Where once the individual was a high achiever, those same high standards set up a new perception of failure as the individual and their fatigued body can no longer perform to the same level.

¹³ It is acknowledged that it is not ideal to compare recalled past behaviour with reports of current behaviour.

Accordingly, it was hypothesised that CFS patients would have high levels of depressogenic thinking, in line with the high levels of psychopathology and particularly depression reported and previously discussed. Further, it was predicted that CFS patients would have high levels of the second factor of depressogenic thinking as measured by the Dysfunctional Attitudes Scale (DAS) - performance evaluation. The latter construct is associated with a rigid focus on performing to a high standard.

The data of the current research support the hypotheses. The CFS group had a comparable level of overall depressogenic thinking (ie incorporating the constructs 'approval by others' and 'performance evaluation') to the depressed group ($p=.264$) and a significantly higher level than the healthy group ($p=.005$).

Further, the CFS group had significantly higher ratings on the 'performance evaluation' set of dysfunctional attitudes than the healthy group ($p<.001$) and a comparable level to the depressed group ($p=.281$). To provide further discriminant validation of the result on the performance evaluation construct, it is relevant to note that on the 'approval by others' construct, there is no significant difference between the CFS group and the healthy group ($p=.127$); the ratings of the CFS group lie between the depressed group and the healthy group. It would appear that the key dysfunctional and depressogenic thinking style of the CFS group is the harsh and rigid adherence to achieving high standards.

In a similar vein, Surawy and others (1995) had proposed a set of cognitions that they had observed amongst a sample of CFS patients in their practice. These included such statements as "I need to achieve to be worthwhile" and "people will only value me if I'm emotionally strong". The predicted results were obtained - the CFS group had higher levels of these self-demanding cognitions than the healthy group ($p<.001$), and a comparable level to the depressed group ($p=.780$).

There is a considerable overlap between the 'performance evaluation' construct of the DAS and constructs of perfectionism. Indeed, Burns (1980) developed a measure of perfectionism based on many of the performance evaluation items of the DAS. Frost and colleagues suggest that there is a critical link between perfectionism and psychopathology which arises not just through the setting of high standards, but through "high standards of performance *which are accompanied by tendencies for overly critical evaluations of one's behaviour*" (1990, p450).

Frost and colleagues (1990) in a series of studies found that there were specific perfectionism constructs which related to psychopathology - 'concern over mistakes' and 'doubting of actions', rather than the setting of high standards *per se*.

Each of the hypotheses relating to perfectionism were borne out by the study data. Overall levels of perfectionism were higher in the CFS group than in the healthy group ($p=.001$) and the CFS group had comparable levels to the depressed group ($p=.707$). More specifically, the 'concern over mistakes' factor and 'doubts about actions' factor were rated more highly in the CFS group than in the healthy group ($p\leq.001$), and at a comparable level to the depressed group ($p\geq.495$).

Again, to provide some differential validation of the findings and to further refine the construct, it was relevant that ratings on the construct 'setting standards' which has *not* been found to be related to psychopathology, did not differ amongst the groups ($p=.414$).

It is interesting that greater numbers of the CFS sample in the current, primary care sample had clinical levels of anxiety, rather than depression. In this light it is relevant to discuss the core dysfunctional beliefs associated with anxiety.

There is much in common between the core dysfunctional assumptions associated with depression and anxiety. While those associated with depression include approval by others and performance evaluation as has been discussed at length above, those encountered in individuals with anxiety include the following:

- *acceptance* - e.g. 'I always have to please others'
- *competency* - e.g. 'I have to do everything perfectly'
- *responsibility* - e.g. 'I'm mainly responsible for peoples' enjoyment when they're with me'
- *control* - e.g. 'I have to be in control at all times'
- *about anxiety itself* - e.g. 'I must be calm at all times and its dangerous to show signs of anxiety' (Clarke 1989).

The first two directly correspond to those found in depression. The last two, in particular reflect the beliefs about coping and being seen to cope noted by Surawy and colleagues (1995). A strong overlap between the cognitions empirically tested in the study and those proposed under Beck's cognitive theory applied to anxiety (Beck 1976) is manifest.

Centrally, it would appear that patients with CFS tend to have rigid, and harsh-on-themselves performance expectations, that are unremitting in the face of forced poorer performance and activity in the context of an illness. Further support for this suggestion is lent by the finding discussed above, that CFS sufferers indicate that they were more critical of themselves during the illness than any of the 'other's' in their lives.

4.2.3 ASSOCIATION BETWEEN SEVERITY OF ILLNESS, AND DEPRESSION AND DEPRESSOGENIC THINKING (HYPOTHESIS 4)

Given Surawy's model (Surawy et al 1995) of fatigue leading to increased avoidance of activity, resulting in a greater sense of not achieving, followed by spurts of activity, and then increased fatigue and so on, it was predicted that more severe CFS symptoms would be associated with greater depression and increased depressogenic thinking.

There was, at best, only weak support for this finding. While there was a weak trend linking the severity of CFS symptoms with depression as measured on the HADS ($r=.25$, $p=.068$), overall symptoms (which also included symptoms of depression), associated better with depression ratings. The latter is to be expected because of confounding between the affective depression symptoms and the affective items on the HADS. Interestingly, perhaps, CFS symptoms were highly predictive of depression scores in the depressed group ($r=.68$, $p<.001$). This possibly points to the high overlap between the two illnesses, particularly in the area of somatic symptoms, and yet differences, in the affective symptoms as has been reported elsewhere (Powell *et al* 1990).

Only one study has found an association between severity of symptoms and outcome (Bonner 1994). The researchers found that a greater number of somatic symptoms, and greater fatigue were associated with poor outcome. The overriding predictor of outcome, was however, the illness attribution to a physical or psychological cause (discussed more fully below) and a psychiatric history.

A similar trend emerged in associating CFS symptoms with depressogenic thinking scores as measured by the DAS. There was a weak trend ($r=.26$, $p=.059$). Clearly, there are more factors relating to depression and dysfunctional attitudes than the somatic CFS symptoms. Suggestive of this is the correlation between overall symptoms and DAS scores in the CFS group ($r=.37$, $p=.012$).

4.2.4 ATTITUDES TO THE ILLNESS, AND LEVELS OF DEPRESSION AND DEPRESSOGENIC THINKING (HYPOTHESIS 5)

4.2.4.1 Illness Attribution

Previous studies have found a strong tendency for CFS patients to have an external attribution for their illness, that is, to attribute the illness to physical causes rather than a psychological basis. Wood and co-workers (1991) and Wessely and Powell (1989) reported 55% and 83%, of their CFS samples, respectively as having a physical attribution for their illness. In the current study, 85% of the CFS group had a mainly physical attribution. By contrast, and consistent with the Wessely study, only 26% of the depressed group had a physical attribution; 74% had a mainly psychological attribution.

It was predicted, on the basis of learned helplessness theory (Abramson *et al* 1978) that CFS patients with an internal illness attribution would have higher levels of depression and depressogenic thinking. Previous studies have found that those with an external illness attribution have a poorer prognosis (Powell *et al* 1990; Butler *et al* 1991; Sharpe *et al* 1992; Bonner *et al* 1994; Wilson *et al* 1994).

Wessely (1991b) cautioned that while an external illness attribution is easier to understand, reduces guilt or self-blame and preserves self-esteem, it also may be misleading. The external illness attribution may obscure symptoms of depression, increase helplessness as it offers no opportunity to control symptoms, offers no treatment and is associated with a decline in self-efficacy. The implication was that an external illness attribution was not a wholly desirable thing and rendered the patient less amenable to treatment. Powell and colleagues (1990) warned that there may also be detrimental effects of an external attribution - when the cause of the illness is seen as untreatable (as was found in their study), then the sequelae of helplessness, increased fatigue and lack of self-efficacy ensue. Powell relates their findings to the Learned Helplessness Model of Depression - "the post-viral states which were claimed by most of our CFS sample as potent, uncontrollable,

aversive and frightening. As such they predict a high rate of depression, which we found. Furthermore, the learned helplessness theory states that attribution to an external cause should lead to preservation of self-esteem” (Half of their CFS sample met RDC criteria for depression; p 670).

The illness attributions did not, however, relate to severity of depression ($p=.385$). While it should be taken into account that only 5 subjects in the CFS group had a mainly psychological attribution, not even a trend was detected associating the illness attribution with severity of depression.

However, there was a trend suggesting that an illness attribution that saw psychological factors as significant was associated with higher levels of *anxiety* in the CFS group ($p=.053$). It would appear from the findings of the current study that an external attribution also protects CFS patients from higher levels of anxiety and its inherent distress.

Consistent with the study’s prediction, there was an association between an internal illness attribution and higher levels of depressogenic thinking ($t=-2.592$, $p=.014$; $r_s=.457$, $p=.004$).

While previous studies have looked at the association between illness attribution and guilt and self-esteem (Powell *et al* 1990), and coping styles and anxiety levels in CFS (Ray 1993), none have reported the association between illness attribution and levels of anxiety and depression *per se*. The Powell study found higher levels of guilt and lower levels of self-esteem in those with an internal attribution. They proposed that “An external style attribution may be exerting a protective influence against certain cognitive changes of depression as compared with an internal style of attribution causing the patient to experience greater psychological distress and lower self-esteem” (p 670).

The results were not clear cut - the expected result was found in that an internal illness attribution was associated with depressogenic thinking and incidentally

with levels of anxiety; however, an internal illness attribution was not found to be associated with levels of depression.

The lack of a finding of an association between depression and the illness attribution as predicted may be attributable to features of the measure used in this study. It should be noted that the HADS - Depression scale largely taps anhedonia and does not include items measuring guilt and self-esteem; accordingly, the scale is inadequate for detecting the latter features often encountered in depression and those specifically predicted by the learned helplessness model of depression. By contrast, the HADS - Anxiety scale taps feelings of being ill at ease and out of control - arguably, the scale of the two most likely to pick up feelings of helplessness and fear. Consistent with the learned helplessness model, there was a trend for the internal illness attribution to be associated with higher ratings of feeling frightened and panicky as assessed by the HADS - Anxiety scale.

An alternative interpretation is that perhaps the self-esteem enhancing and guilt reducing benefits of having an external illness attribution balanced out the increased aversiveness and frightening nature of having an unknown physical illness as described by Powell and Wessely - leading to a neutral finding. Conversely, however, contrary to Powell and Wessely's implications, it seems intuitively difficult to follow the logic of assuming that a physical or medical cause is more aversive and uncontrollable than a psychological cause of an illness. The latter could be seen as more aversive, as some would feel a greater level of responsibility for succumbing to the illness, and as the individual did not seek to be ill, it could be perceived as no more controllable than a physically based illness. As Powell and colleagues point out, "One cannot over emphasize that it is impossible to judge the 'correctness' of the attributional style found in CFS or depression, especially in the light of current neurobiological discoveries in psychiatry" (Powell et al 1990, p670).

On common ground with Powell and Wessely, as will be addressed below further in a discussion of therapeutic implications of the findings, an illness attribution

that sees psychological methods as useful in *dealing with* symptoms of CFS, would be beneficial in helping increase feelings of controllability of the illness.

The findings, on balance indicate that an internal illness attribution is associated with higher levels of anxiety and depressogenic thinking; the expected association with higher levels of depression did not materialise, possibly because of the nature of the measure of depression used in the study.

4.2.4.2 CFS Illness Beliefs

Surawy and colleagues (1985) proposed a set of illness beliefs that they observed in over 100 CFS patients. These included items such as 'activity makes me feel worse', 'I can do things to the same standard as I used to', 'I should strive to achieve my previous level of performance and activity', 'because of my illness I feel that I am being left behind', 'I feel that it is important to be seen to cope', 'I should rest as much as possible to get better' and 'people think I'm lazy if I don't achieve as much as I used to'. It was proposed that adherence to these set of beliefs would associate with higher levels of depression and depressogenic thinking. According to Surawy's proposed model, avoidance of activity tends to lead to feelings of failure to live up to standards, then bursts of activity and then increased symptoms and poor performance - a good recipe for a maintenance cycle of depression.

These illness beliefs were largely subscribed to in the CFS sample in the current study, and interestingly, equally overall by both the CFS group and the depressed group - overall ratings indicated 'agree slightly' with the set of beliefs. However, the CFS group more strongly adhered to the belief that 'activity makes me feel worse' - a median rating of 'agree very much' for the CFS group and 'disagree slightly' in the depressed group.

The expected association between adherence to the illness beliefs and higher levels of depression was only supported at a weak level. There were no

significant differences in adherence to the illness beliefs and different categories of severity of depression in any of the groups ($p > .067$). However, weak correlations in the predicted direction were found in the CFS group with HADS - Depression ($r = -.275$, $p = .050$), HADS - Anxiety ($r = -.271$, $p = .053$), and with depressogenic thinking as measured by the DAS ($r = -.304$, $p = .034$). The same results were found in the depressed sample.

The association between adherence to the overall set of illness beliefs and functional impairment were also explored. No significant correlations were found. However, when the single item 'activity makes me feel worse' was examined, there was a moderate association between adherence to that belief and higher levels of functional impairment in the CFS group ($r = -.476$, $p = .002$) and also in the depressed group ($r = -.561$, $p = .001$).

Ray and colleagues (1993) in their study examining illness management of CFS identified a factor of 'maintaining activity'. While their study looked at reported behaviour rather than beliefs, the findings were consistent with those of the present study - they found that decreased maintenance of activity was associated with higher levels of functional impairment.

In summary, support for Surawy's proposal that CFS patients adhered to a specific set of illness beliefs - the need to strive, cope, put on a front and to avoid activity was found. Further, it was hypothesised in this study that those illness beliefs would further exacerbate a maintenance cycle of depression, as evident by higher levels of depression and depressogenic thinking in those more strongly agreeing with the illness beliefs. Weak support was found for the latter, with modest correlations in the predicted direction. While no specific predictions were made regarding an association between the illness beliefs and functional impairment, it would be expected that any negative impact of the illness beliefs would manifest in greater functional impairment in those with greater accordance with the beliefs. However, while the item 'activity makes me feel worse' was associated with greater impairment, in line with the finding of Ray *et al*, the overall set of illness beliefs did not.

One explanation of the only weak support for the stated hypothesis is that the items are heterogeneous in nature and cover a range of beliefs - from 'activity makes me feel worse' to 'I feel it is important to be seen to cope'. The belief about activity making one feel worse seems to be a central one and is one that needs to be explored in any treatment program as is discussed further below. However, it would appear that the illness beliefs as proposed by Surawy and others (1995), while prevalent may not be the central ones in a maintenance cycle of depression in CFS - the pervasive and ubiquitous cognitions as assessed by the DAS relating to rigidly meeting high standards may be more central and more powerful, and cover a broader range of situations than the illness *per se*.

4.2.5 FACTORS DISTINGUISHING THE CFS GROUP FROM THE DEPRESSED GROUP

Discriminant function analysis was conducted to further explore the components of CFS. Demographic variables, illness variables, measures of psychopathology and attitudinal variables were entered into the analysis, designed to select the variables that best distinguished the CFS sample from the depressed sample. Direct and stepwise analyses were conducted.

Wessely and Powell (1989) conducted a study with patients with CFS, depression or neuromuscular illnesses and *inter alia* conducted a discriminant function analysis to determine if they could correctly classify CFS patients from the other two groups. They found that when illness symptoms and measures of psychopathology were entered, about half of the CFS cases were classified with the neuromuscular group who were also psychiatrically ill; about half with the depressed group; and only 9% with the neuromuscular group without psychiatric illness. They concluded that on symptoms alone, half of the CFS group could not be distinguished from the depressed group. They then examined the role of illness attribution and found that almost complete separation of the CFS and depressed group was obtainable with that variable (18/21 CFS; 19/20 depressed).

The approach used in the current study differed from that used in the Wessely and Powell study, in that the discriminant function analysis was conducted on the CFS and depressed groups (rather than the equation that was derived from the other groups being subsequently applied to the CFS group), and a broader range of variables were entered. The two groups could readily be distinguished. As found in Wessely's and Powell's study, illness attribution was the single most useful variable in distinguishing the groups; indeed when a stepwise analysis was conducted, it was the only variable entered as no other variables explained sufficient further variance. However, when an analysis was conducted omitting illness attribution, a comparable fit and classification was achieved in a three step solution. The three variables that separated the two groups were - the CFS criteria score, the depression criteria score and the HADS - Anxiety score, entered in that order. This resulted in a correct classification rate of 92% of the CFS cases and 67% of the depressed cases, and an overall correct classification rate of 81%. By contrast, the illness attribution alone solution led to a poorer CFS classification of 81% but a better depressed classification rate of 74%.

When discriminant function analysis was applied to the three groups - CFS, depressed and healthy, a two variable solution was obtained¹⁴. Again, CFS criteria and depression criteria separated the three groups most effectively - HADS - Anxiety was not found to add sufficiently to the factor solution in this case. Notably, the CFS group and the healthy group were correctly classified, but the depressed group had a significant number of misses - only half were correctly classified and the remainder were evenly misclassified to the CFS and healthy groups.

It is interesting to note that it was the measure of depression symptoms rather than the HADS - Depression scores that explained sufficient variance to be entered. This is possibly because the range of depression symptoms canvassed included mood and cognitive symptoms, whereas the HADS - Depression scale

includes only anhedonia and none of the self-esteem and guilt components that Powell and colleagues (1990) found to discriminate between affective and CFS patients.

In summary, as others have concluded there is a large overlap between CFS and factors of depression and yet differences (Jenkins 1991; Ray 1991). However, while the measure of depression - HADS - Depression was not significant in separating the two groups in the current study, there are apparent differences in the *illness symptoms* of the two illnesses - while fatigue is common to both, the CFS patients have greater levels of the other somatic CFS symptoms and the depressed patients have greater levels of the cognitive and affective elements of the depression spectrum - this is borne out by the ability of the symptom scores to separate the two illnesses in the majority of cases and well beyond the level expected by chance alone.

4.3 LIMITATIONS OF THE STUDY

This study, in part, overcomes some of the limitations identified in other studies which explore the characteristics of CFS patients in tertiary referral centres - “A further limitation of this study [the Powell study] is the nature of the study group which, because of both duration and severity, is unrepresentative of the CFS sufferers seen in primary care.....the results cannot be generalised to those seen outside the specialist setting” (Powell *et al* 1990, p 669).

Other researchers have criticised their studies on the basis that their CFS samples and comparative samples have been drawn through different channels which arguably adds confounding error. For example the Powell and co-workers study (1990) noted that their CFS sample was drawn from patients from a tertiary referral centre for neurology, while their depressed sample was drawn from a

¹⁴ Note that the full range of variables could not be entered as they did not apply to the healthy group - illness attribution, length of illness and illness beliefs.

psychiatric hospital. The current study, in obtaining subjects from the same source, i.e. general practitioners, has overcome that difficulty.

However, as with any cross-sectional and questionnaire based design the current study has its limitations. By obtaining subjects through general practitioners and in maintaining confidentiality, it was not feasible to obtain contact details to follow up doctor's patients who did not return their questionnaires. Further, as the doctors did not complete the demographic details of those given the questionnaire (although requested to), it was not possible to determine if there was sampling bias in the returns. It can be expected that there would be some bias in that perhaps better educated people returned questionnaires. It could also be expected that the more seriously depressed or otherwise ill patients in the clinical groups would be less likely to complete and return the questionnaires. The latter may be reflected in the smaller number of returns in the depressed sample. On the positive side, it assisted obtaining subjects in the two clinical groups who were of comparable severity of illness.

It would have been desirable to have a measure of reliability in the GPs' diagnosis of CFS and depression. However, while verification of the diagnoses through a second assessment would have strengthened the results, it was not feasible given the constraints on GPs' time; patient time and confidentiality; and the lack of funding for additional medical assessments. Arguably, the current design can be said to represent diagnoses as they typically occur in primary care settings.

It should also be borne in mind that the information provided, apart from the initial screening by general practitioners, was all self-report data. This means that it is subjective in nature and open to the associated bias. However, the symptoms of CFS *are* descriptive at this stage, as no physiological tests or biological markers have been found to be diagnostic (Krupp et al 1991; Wessely 1991). In a related vein, it would have been useful in the current study to have obtained from the doctors information about patients medication, particularly if anti-depressant medication had been prescribed. However, given that doctors, did not have sufficient time to provide the basic demographic information requested of those

given a questionnaire, it is unlikely that they would have had the time to complete information regarding medication.

Wessely and Powell (1989) and Powell and others (1990) commented on the information bias inherent in their studies. Their studies, similar to the current study, involved comparisons between CFS patients and depressed patients. They noted that the depressed subjects tended to report their current episode of illness but the CFS subjects tended to refer to the illness from its onset. This same limitation is likely in the current study, where the CFS group had reported being ill for longer. However, it should be noted that in both groups the typical length of illness was equal at 12 months.

The sample size of the study was not large and this has implications for the statistical power of the analyses involved. However, every attempt was made in following up GPs to increase the sample size; indeed several extra months were devoted to this pursuit. While the sample size by absolute terms was not large, it should be considered alongside the reported prevalence findings in the Australian study conducted in 1990 (Lloyd *et al* 1990). In that study, 42 cases were detected by 26 medical practitioners in a population of 114,000. Given that the Canberra/Queanbeyan area has a population of some 330,000, (ABS 1995, Cat. No. 1313.8, Table 9; p1) only some 120 patients would be expected in the whole area. The present study only included a sample of general practices - those GPs who replied indicating that they were interested in participating in the study. According to the findings of the prevalence study, the current sample of 37 with CFS netted some 30% of the CFS population. Alternatively, the real incidence is much higher than the .04% reported by Lloyd and colleagues. The latter is a more likely conclusion (Pawlikowska *et al* 1994).

5. CONCLUSIONS AND THERAPEUTIC IMPLICATIONS

Elucidating ways to better help people with CFS to cope with their illness was the overriding objective of this research. The author was struck by the pervasive sense of helplessness associated with the medical approach to CFS - the 'best' treatment has consisted of "establishing the absence of treatable disease; acknowledging the reality of the patient's illness; diagnosing "post infectious" or "idiopathic" fatigue; and optimistic reassurance about prognosis" (Sharpe *et al* 1992, p148). The latter is noted in conjunction with gloomy reports about patients with the typical long and relapsing course of the illness (Bonner 1994). The element of "establishing the absence of treatable disease", clearly implies that CFS is seen as an untreatable illness; it is hardly surprising with this level of perceived helplessness that the incidence of depression and anxiety is high in patients with CFS.

To a modest extent, the current study attempted to determine whether there was a role for cognitive behaviour therapy in CFS. Authors such as Wessely, Powell, Bonner, Chalder, Butler, David and Surawy have provided a glimmer of hope with their research into possible CFS management programs. Wessely and colleagues (1991) proposed a compelling cycling model as outlined in the introduction. He argued a role for fatigue originating from a viral or other cause, followed by fatigue, then inactivity, symptoms (e.g. fatigue on exertion), avoidance of activities, more symptoms, loss of control/demoralisation, depression, leading to further fatigue and so on. Surawy and colleagues (1995) added a step to account for bursts of activity that they had observed in their CFS patients. They attributed the bursts of activity to feelings of failure about not living up to standards.

The current study attempted to empirically test these proposals and to test a proposed further component to the model - the possible maintaining role in the

illness of the pervasive depressogenic construct 'performance evaluation' and related perfectionist cognitions.

The study did not attempt to 'buy into' the debate on the aetiology of the illness, but rather to examine ways in which patients could be assisted, regardless of its pathogenesis. While the study employed the use of a depressed clinical control, it was not its primary purpose to argue for the sameness or differences between the two diagnoses. The depressed group was used largely to provide a benchmark for degree of depressogenic thinking, hypothesised to be also prevalent in patients with CFS. However, consistent with previous studies, it was clear that even when somatic symptoms are not included in measures of psychopathology, the clinical levels of psychopathology are high - 57% of the sample had either depression or anxiety, mostly the latter, providing a minimum level of psychiatric 'caseness'. This is markedly higher than the levels found in other physical illnesses (Wessely and Powell 1989; Wood *et al* 1991). This provides *prima facie* evidence that psychological factors are implicated for many individuals with CFS, although they are not necessarily causal or sufficient for the development of the illness. The corollary to this is that 43% did not have a clinical level of psychiatric illness - indicating that non psychological factors are implicated for many with CFS.

So then, what is the role, if any, for cognitive behaviour therapy? Wessely and colleagues (1991), and Surawy and colleagues (1995) have pointed to the role of specific illness beliefs in maintaining symptoms in CFS - 'CFS is a disease and activity exacerbates the illness'; 'more activity will cause serious harm'; 'I did more but feel exhausted so I must have done more muscle damage'. Central to these is the belief that activity is to be avoided. This notion has been furthered by advice from doctors and self-help groups who advocate rest. Certainly, this study has found that CFS patients in primary care maintain this view. As proposed by Wessely and others in their chapter on management of the illness (Wessely *et al* 1991), a program of gently graded, client chosen activities are recommended to both redress physical deconditioning and to provide some of the 'pleasures' and positives back into the patient's life, in line with behavioural and integrative theories of depression (Lewinsohn *et al* 1985). For those who are not depressed

or anxious, this procedure can help provide an improved quality of life and can be seen as an important depression and anxiety preventative measure. As one of Woodward's subjects said "Going to bed might ease my body but it's dreadful for my morale. So I try to be part of the world and what is going on even though it takes so much effort and I am not really there at all. Had I gone to bed I think I might have packed it in for good or never got going again" (1993, p 88). A key cognitive and educative component of this aspect of therapy is the associated information provided about muscle deconditioning, and the importance of keeping a balance between the debilitating aspects of the illness and maintaining pleasure in life.

Surawy's and colleagues' observation that CFS patients tend to hide their emotions and to feel that they should be seen to cope was also supported by the findings of the current research. CFS sufferers had a high level of these beliefs, as did the depressed sample. It would seem important in therapy to do two things in this regard - firstly to challenge these beliefs when identified in therapy, and secondly to provide an outlet for such emotions. The latter would have the extra benefit of providing the opportunity for behavioural experiments - 'I lost my cool in therapy, and I'm still OK'. An account by a subject in Woodward's study eloquently makes this point "Now when I look back I realise that I had only been separated from my husband for six months when I got glandular fever. I realise I must have had a lot of buried emotions. I was always an optimist and I always looked to the future. I had said well that's over now and I'm going to do all these things. So I was stressed at that time but not acknowledging all the feelings I had" (1993, p 87). These particular beliefs correspond with the assumptions of staying in control and 'appearing calm' constructs of the anxiety dysfunctional attitudes proposed under Beck's cognitive theory (Clarke 1989).

To this point, the current research has confirmed and empirically tested adherence to the illness set of beliefs proposed by Wessely and colleagues (1991) and Surawy and colleagues (1995). However, the contribution of the findings of this study is to expand the cognitive component of the therapy protocol proposed by Wessely and colleagues, by empirically testing the suggestions across the

literature that CFS patients tend to be 'driven', 'achievers' and have unreasonably high standards.

Strong evidence was provided in the current study of these pervasive harsh and self-deprecating tendencies across different measures - on the Dysfunctional Attitudes Scale, a state measure of depressogenic thinking - particularly in the factor relating to performance evaluation; on the measures of perfectionism - overall and on the scales 'concern over mistakes' and 'doubts about actions'; on the measure of previous 'hard-driven' behaviour; and even in their own assessment of how critical they had been of themselves in their illness. Some base evidence was provided in the gross measure of achievement - educational levels attained where CFS patients exceeded the educational levels of their peers, and in their pre-illness 'driven' behaviour.

A proposed model for the treatment of depression and anxiety found in patients with CFS follows. It incorporates elements from Wessely and colleagues (1991) and Surawy and colleagues (1995) with the notable addition of the element relating to unrelenting standards and self-criticism - pivotal in the cycle and in treatment.

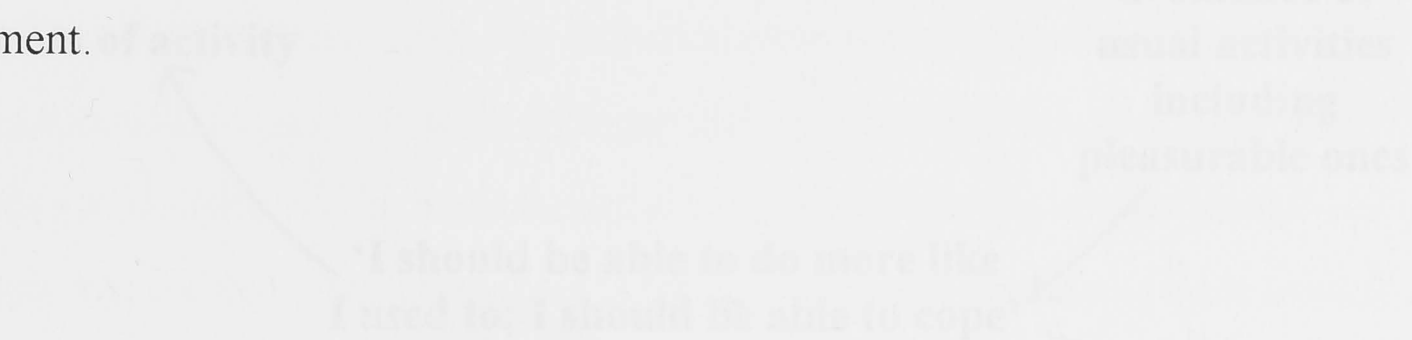


Figure 5 A Proposed Model of Management of Depression and Anxiety in CFS

Again, while not all CFS patients will manifest perfectionistic and performance evaluative standards, the obtained data indicate that cognitive techniques should be used to maintain the level of such cognitive assumptions. This important element of therapy can be used in conjunction with the return of goals for therapy and the pursuing of pleasurable activities. Significant effort may be required to challenge core beliefs that there is no time or role for doing activities purely for their intrinsic enjoyment, but rather that they need to be done for the purpose of doing the activity well. Patients may need 'taking time to seek the rules' therapy.

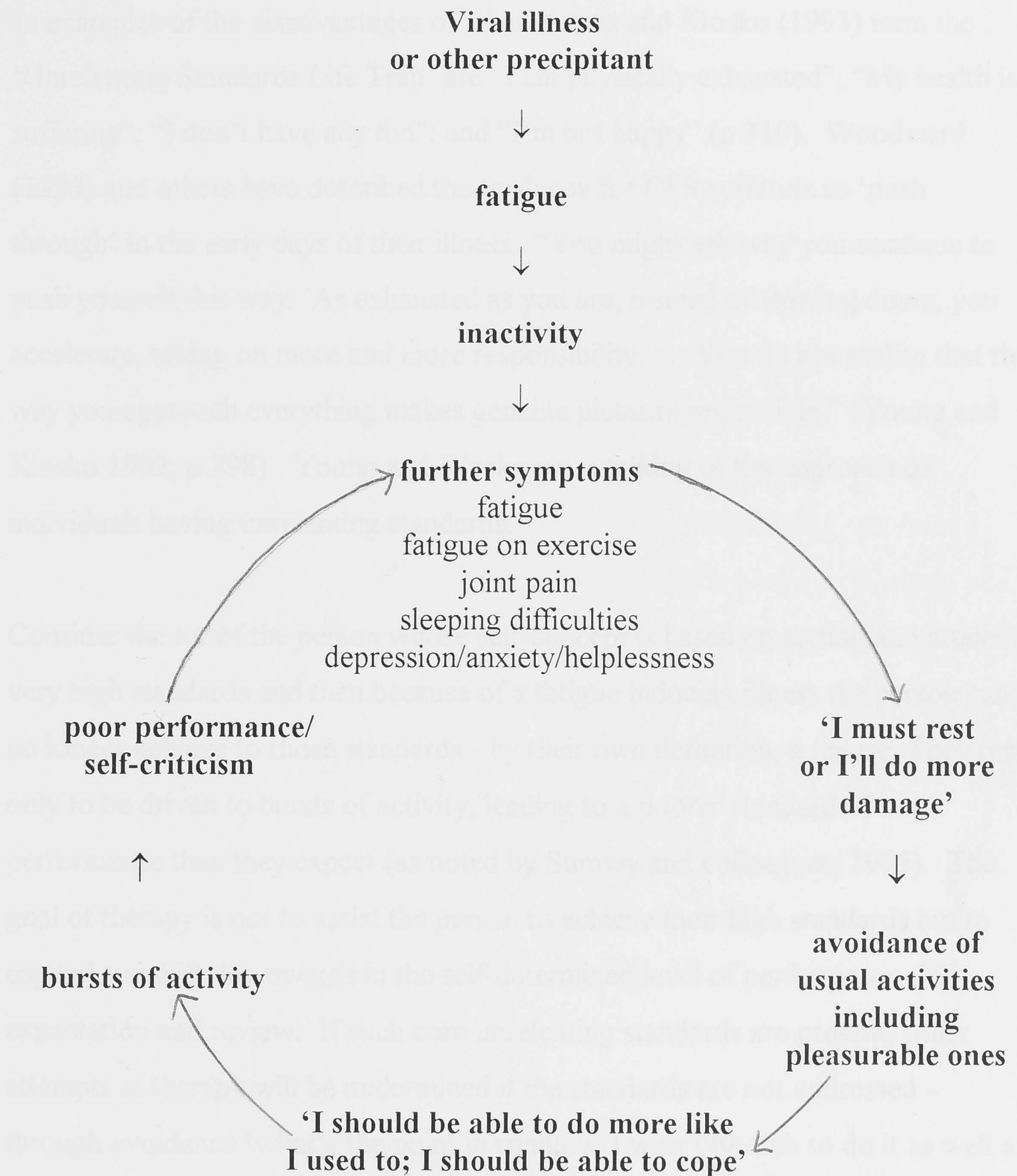


Figure 5 A Proposed Model of Maintenance of Depression and Anxiety in CFS

Again, while not all CFS patients will manifest perfectionistic and performance evaluative standards, the obtained data indicate that cognitive techniques should be used to ascertain the level of such cognitive assumptions. This important element of therapy can be used in conjunction with the setting of goals for therapy and the pursuing of pleasurable activities. Significant effort may be required to challenge core beliefs that there is no time or role for doing activities purely for their intrinsic enjoyment, but rather that they are to be done for the purpose of doing the activity well. Patients may need 'taking time to smell the roses' therapy

to counteract their unrelenting standards, feeling of failure inducing tendencies. In examples of the disadvantages of what Young and Klosko (1993) term the 'Unrelenting Standards Life Trap' are "I am physically exhausted"; "My health is suffering"; "I don't have any fun"; and "I'm not happy" (p 310). Woodward (1993) and others have described the tendency for CFS sufferers to 'push through' in the early days of their illness. "You might ask why you continue to push yourself this way. As exhausted as you are, instead of slowing down, you accelerate, taking on more and more responsibility.....You do not realise that the way you approach everything makes genuine pleasure impossible." (Young and Klosko 1993, p 298). Young and Klosko were talking of the approach of individuals having unrelenting standards.

Consider the lot of the person whose self-concept is based on setting and attaining very high standards and then because of a fatigue inducing illness the person can no longer achieve to those standards - by their own definition, a failure. They rest, only to be driven to bursts of activity, leading to a poorer standard of performance than they expect (as noted by Surawy and colleagues, 1995). The goal of therapy is not to assist the person to achieve their high standards but to engender a shift downwards in the self-determined level of performance expectation and review. If such core unrelenting standards are present, other attempts at therapy will be undermined if the standards are not addressed - through avoidance 'what's the point in trying it, I won't be able to do it as well as I used to or as well as I'd like to'; through minimising achievements - goals attained in therapy will be disregarded; and through levels of activity which are in bursts rather than spread out and of gentle proportions.

It would not seem to be necessary, desirable or necessarily accurate to attempt to dissuade CFS patients that their illness is of physical origins. As has been canvassed elsewhere (Powell *et al* 1990), an external attribution is neither right nor wrong and is associated with less guilt and higher levels of self-esteem. What is important in therapy is to increase the patient's sense of control over symptoms and a sense of control and involvement in a program of better *coping* with the illness. In line with learned helplessness theory, this provides an internal

attribution - personal responsibility for the *positive* outcome of therapy as well as a decline in perceived helplessness. According to the theory, such a perspective is depression (and anxiety) minimising.

Further research is highly desirable and should occur in two key areas. Firstly, the role of anti-depressants has not been adequately addressed, although widely conflicting views are held about the efficacy of medication in CFS (Jenkins and Mowbray 1991). Secondly, while cognitive behavioural treatment trials have been conducted, they have either not been conducted using an appropriate treatment protocol (Lloyd et al 1993), or have not been methodologically rigorous (Butler et al 1991; Bonner et al 1994). A rigorous study, conducted with a treatment protocol that includes the components outlined by Wessely and colleagues (1991) and Surawy and colleagues (1995), and incorporating the broader depressogenic attitudes found to be prevalent and pervasive in the current study, would seem to be required.

Many insights were provided by the subjects in the study about assistance found useful in dealing with CFS, in line with the quantitative findings of the study: "lowering standards and gradual increase in activity as bed rest did not help", "understanding of limitations, reducing expectations, family counselling, depression counselling, relaxation and stress management" and "learning to relax my own standards and to stop perceiving myself as not coping". As has been pointed out by others (Wessely 1991), it is an indictment of society's attitude to illnesses that are not manifest by broken bones, other visually apparent afflictions, or physical markers, that often makes the lot of those experiencing CFS so much more difficult.

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Material for GPs

Attachment 1

Material for GPs

Australian National University



PSYCHOLOGICAL SUPPORT IN CHRONIC FATIGUE SYNDROME

About This Study

This study is designed to help determine in which ways health professionals can provide psychological support to people with Chronic Fatigue Syndrome (CFS).

You may have been asked to complete this questionnaire because you have CFS; or because you have depression or are a healthy person whose information is needed as a comparison.

Participating in the study will involve completing the questionnaire and signing the attached consent form. Your signed consent is necessary to indicate your agreement to participate in the study. Although your signature appears on the consent form, it will be detached from the completed questionnaire before any data processing commences. In this way there will be no identifying information attached to any completed form, and thus anonymity and confidentiality is assured.

You may also wish to be informed of the outcome of the study and may wish to receive a summary of the results. If you do, please complete the slip indicating your interest. It similarly will not be retained with the completed questionnaire.

Instructions

1. Please sign the consent form.
2. Complete the questionnaire. If you need any assistance with completing the questionnaire, please contact me at the Psychology Department, ANU on phone 249 2795. If you find the questionnaire tiring, please have breaks and complete it in stages.
3. If you are interested in receiving feedback about the study, complete the interest in results form.
4. Return the consent form and questionnaire in the return envelope within a week or so of receiving the questionnaire. Also enclose the interest in results form if you wish.

Thankyou

I greatly appreciate your assistance and thank you most sincerely for your generosity in providing your time to complete the questionnaire. I trust that the results of this study will assist people with Chronic Fatigue Syndrome in the future.

Juanita Kolaric
Master of Clinical Psychology Student
Australian National University

Please return with the questionnaire:

CONSENT FORM

I understand the nature of the study and consent to completing the form. I am aware that I may withdraw this consent at any stage during the study.

Signature: _____

Date: ___/___/___

INTEREST IN RESULTS FORM
(Optional)

I am interested in receiving a summary of the results when the study is complete:

Name: _____

Address: _____

BACKGROUND INFORMATION

1. Age: _____

2. Sex: ☐ Male ☐ Female

Occupation

3. Are you currently doing paid work? ☐ Yes ☐ No

4. What is your usual occupation:

<input type="checkbox"/> Manager or administrator (eg general or specialist manager, farm manager)
<input type="checkbox"/> Professional (eg scientist, school teacher, building professional, health professional)
<input type="checkbox"/> Para-professional (eg technical officer, nurse, police officer)
<input type="checkbox"/> Tradesperson (eg electrical or building trades)
<input type="checkbox"/> Clerk (eg general clerk, stenographer or typist, receptionist)
<input type="checkbox"/> Salesperson or personal service worker (eg insurance, sales, real estate)
<input type="checkbox"/> Plant and machine operator or driver (eg road and rail transport driver, machine operator)
<input type="checkbox"/> Labourer or related worker (eg trades, factory hands, agricultural labourers, construction and mining labourers)
<input type="checkbox"/> Unpaid work (tick if have never done paid work, or if have not done paid work for 10 or more years)(eg home keeping)

Education

5. How old were you when you left school?

<input type="checkbox"/> Still at secondary school	<input type="checkbox"/> 16 years
<input type="checkbox"/> Did not go to school	<input type="checkbox"/> 17 years
<input type="checkbox"/> 14 years or younger	<input type="checkbox"/> 18 years
<input type="checkbox"/> 15 years	<input type="checkbox"/> 19 years or older

6. What is the highest qualification that you have attained since leaving school?

<input type="checkbox"/> Skilled vocational certificate	<input type="checkbox"/> Bachelor degree
<input type="checkbox"/> Basic vocational certificate	<input type="checkbox"/> Post graduate diploma
<input type="checkbox"/> Associate diploma	<input type="checkbox"/> Higher degree
<input type="checkbox"/> Undergraduate diploma	<input type="checkbox"/> Not applicable

Marital status

7. What is your present marital status?

<input type="checkbox"/> Never married	<input type="checkbox"/> Divorced
<input type="checkbox"/> Married/ defacto	<input type="checkbox"/> Widowed
<input type="checkbox"/> Separated but not divorced	

Sport

8. Have you are ever played sport at a highly competitive level (eg at State or National level)?

☐ Yes ☐ No

Background of Parents

9. What are your parents' usual occupations (if a parent is retired or deceased please indicate their previous occupation):

Father	Mother	Occupation
<input type="checkbox"/>	<input type="checkbox"/>	Manager or administrator (eg general or specialist manager, farm manager)
<input type="checkbox"/>	<input type="checkbox"/>	Professional (eg scientist, school teacher, building professional, health professional)
<input type="checkbox"/>	<input type="checkbox"/>	Para-professional (eg technical officer, nurse, police officer)
<input type="checkbox"/>	<input type="checkbox"/>	Tradesperson (eg electrical or building trades)
<input type="checkbox"/>	<input type="checkbox"/>	Clerk (eg general clerk, stenographer or typist, receptionist)
<input type="checkbox"/>	<input type="checkbox"/>	Salespersons and personal service workers (eg insurance, sales, real estate)
<input type="checkbox"/>	<input type="checkbox"/>	Plant and machine operator or driver (eg road and rail transport driver, machine operator)
<input type="checkbox"/>	<input type="checkbox"/>	Labourer or related worker (eg trades assistant, factory hand, agricultural, construction and mining labourer)
<input type="checkbox"/>	<input type="checkbox"/>	Unpaid work (eg home keeping)
<input type="checkbox"/>	<input type="checkbox"/>	Unknown

10. How old were your parents when they left school?

Father	Mother	
<input type="checkbox"/>	<input type="checkbox"/>	Did not go to school
<input type="checkbox"/>	<input type="checkbox"/>	14 years or younger
<input type="checkbox"/>	<input type="checkbox"/>	15 years
<input type="checkbox"/>	<input type="checkbox"/>	16 years
<input type="checkbox"/>	<input type="checkbox"/>	17 years
<input type="checkbox"/>	<input type="checkbox"/>	18 years
<input type="checkbox"/>	<input type="checkbox"/>	19 years or older
<input type="checkbox"/>	<input type="checkbox"/>	Don't know

11. What is the highest qualification that your parents attained since leaving school?

Father	Mother	
<input type="checkbox"/>	<input type="checkbox"/>	Basic vocational certificate
<input type="checkbox"/>	<input type="checkbox"/>	Skilled vocational certificate
<input type="checkbox"/>	<input type="checkbox"/>	Associate diploma
<input type="checkbox"/>	<input type="checkbox"/>	Undergraduate diploma
<input type="checkbox"/>	<input type="checkbox"/>	Bachelor degree
<input type="checkbox"/>	<input type="checkbox"/>	Post graduate diploma
<input type="checkbox"/>	<input type="checkbox"/>	Higher degree
<input type="checkbox"/>	<input type="checkbox"/>	Not applicable
<input type="checkbox"/>	<input type="checkbox"/>	Don't know

DETAILS OF ILLNESS

1. During the **LAST MONTH** have you suffered from (please circle a number for each symptom):

	never	occasionally	frequently	everyday
1. Muscle weakness	0	1	2	3
2. Muscle pain/ discomfort	0	1	2	3
3. Fatigue after exercise lasting more than one day	0	1	2	3
4. Feeling physically tired and drained even after resting	0	1	2	3
5. Being noticeably slowed down	0	1	2	3
6. Noticeable agitation or restlessness	0	1	2	3
7. Chills or mild fever	0	1	2	3
8. Sore throat	0	1	2	3
9. Swollen glands	0	1	2	3
10. Headaches	0	1	2	3
11. Joint pains	0	1	2	3
12. Irritation by light	0	1	2	3
13. Blurred or double vision	0	1	2	3
14. Forgetfulness	0	1	2	3
15. Irritability	0	1	2	3
16. Confusion	0	1	2	3
17. Inability to think clearly	0	1	2	3
18. Inability to concentrate	0	1	2	3
19. Depressed mood	0	1	2	3
20. Feeling worthless	0	1	2	3
21. General feelings of guilt	0	1	2	3
22. Feeling the future is bleak	0	1	2	3
23. Recurrent thoughts of death	0	1	2	3
24. Lack of interest or pleasure in most activities	0	1	2	3
25. Inability to sleep	0	1	2	3
26. Sleeping too much	0	1	2	3
27. Reduced appetite	0	1	2	3
28. _____ (other - please specify)	0	1	2	3

2. Which year did a doctor first diagnose your CFS? 19__

3. How long have you been ill with CFS? ____ yrs ____ mths

4. What stage of the illness do you consider that you are at?

- ☐ Beginning
- ☐ In its midst
- ☐ Recovery
- ☐ Don't know

5. Is your condition:

<input type="checkbox"/> definitely physical
<input type="checkbox"/> physical but psychological factors have some importance
<input type="checkbox"/> equally physical and psychological
<input type="checkbox"/> mainly psychological
<input type="checkbox"/> don't know

6. In which year was the worst six months of your illness (ie when has the CFS been its worst so far)? 19__

7. How critical of you were the following people during that worst six months of having CFS?
(Please circle a number for each person(s))

	not at all critical	a little critical	quite critical	very critical	not relevant
1. Partner	0	1	2	3	4
2. Mother	0	1	2	3	4
3. Father	0	1	2	3	4
4. Own children	0	1	2	3	4
5. Other family members	0	1	2	3	4
6. Friends	0	1	2	3	4
7. Colleagues	0	1	2	3	4
8. Doctors	0	1	2	3	4
9. Acquaintances	0	1	2	3	4
10. Yourself	0	1	2	3	4

8. How supportive of you were the following people during that worst six months of having CFS?

	completely un- supportive	a little supportive	quite supportive	very supportive	not relevant
1. Partner	0	1	2	3	4
2. Mother	0	1	2	3	4
3. Father	0	1	2	3	4
4. Own children	0	1	2	3	4
5. Other family members	0	1	2	3	4
6. Friends	0	1	2	3	4
7. Colleagues	0	1	2	3	4
8. Doctors	0	1	2	3	4
9. Acquaintances	0	1	2	3	4
10. Yourself	0	1	2	3	4

9. During the **LAST MONTH**, how much has having CFS affected you in the following areas (please circle the appropriate number):

<u>Family/home management</u> This category refers to activities related to the home or family. It includes chores or duties performed in and around the house and errands or favours for other family members (eg driving children to school)	0 not at all	1	2	3	4	5	6	7	8 very severely - cannot do it
<u>Ability to work</u> This category refers to activities that are part of or directly related to one's job. This includes non-paying jobs as well, such as that of home-maker or volunteer worker, and activities as a student	0 not at all	1	2	3	4	5	6	7	8 very severely - cannot do it
<u>Self-care</u> This category includes activities which involve personal maintenance and independent daily living (eg taking a shower, getting dressed, driving oneself etc)	0 not at all	1	2	3	4	5	6	7	8 very severely - cannot do it
<u>Social Leisure</u> This category refers to activities which involve participation with friends and acquaintances and family members outside your home. It includes parties, theatre, concerts, dining out, meeting with friends at home or out, and other social functions	0 not at all	1	2	3	4	5	6	7	8 very severely - cannot do it
<u>Private Leisure</u> This category includes hobbies, sports and other leisure time activities	0 not at all	1	2	3	4	5	6	7	8 very severely - cannot do it

10. Feelings play an important part in most illnesses. Following are 14 questions which relate to how you feel. Read each item and circle the reply which comes closest to how you have been feeling in the **PAST WEEK**. Your immediate reaction is usually accurate so there is no need to take too long over your responses.

A. I feel tense or 'wound up'

- ③ Most of the time
- ② A lot of the time
- ① From time to time, occasionally
- ④ Not at all

B. I still enjoy the things I used to enjoy

- ④ Definitely as much
- ① Not quite so much
- ② Only a little
- ③ Hardly at all

C. I get sort of frightened feeling as if something awful is about to happen

- ③ Very definitely and quite badly
- ② Yes, but not too badly
- ① A little, but it doesn't worry me
- ④ Not at all

D. I can laugh and see the funny side of things

- ④ As much as I always could
- ① Not quite so much now
- ② Definitely not so much now
- ③ Not at all

E. Worrying thoughts go through my mind

- ③ A great deal of the time
- ② A lot of the time
- ① Not too often
- ④ Very little

F. I feel cheerful

- ③ Never
- ② Not often
- ① Sometimes
- ④ Most of the time

G. I can sit at ease and feel relaxed

- ④ Definitely
- ① Usually
- ② Not often
- ③ Not at all

H. I feel as if I am slowed down

- Nearly all the time ③
- very often ②
- Sometimes ①
- Not at all ④

I. I get a sort of frightened feeling like 'butterflies' in the stomach

- Not at all ④
- Occasionally ①
- Quite often ②
- Very often ③

J. I have lost interest in my appearance

- Definitely ③
- I don't take as much care as I should ②
- I may not take quite as much care ①
- I take just as much care as ever ④

K. I feel restless as if I have to be on the move

- Very much indeed ③
- Quite a lot ②
- Not very much ①
- Not at all ④

L. I look forward with enjoyment to things

- As much as I ever did ④
- Rather less than I used to ①
- Definitely less than I used to ②
- Hardly at all ③

M. I get sudden feelings of panic

- Very often indeed ③
- Quite often ②
- Not very often ①
- Not at all ④

N. I can enjoy a good book or radio or television programme

- Often ④
- Sometimes ①
- Not often ②
- Very seldom ③

APPROACH AND ATTITUDES

1. How would you describe your style of behaviour **PRIOR** to developing CFS?

(Decide which of the two opposite descriptions you agree with and then indicate how strongly you agree by circling the appropriate number. If you do not agree with either, circle '0'. Eg If you thought that before your illness you were rushed often but not always, you would circle:)

1. Never rushed 3 2 1 0 1 (2) 3 Always rushed)

1. Never rushed	3	2	1	0	1	2	3	Always rushed
2. Would go 'all out' to get things done	3	2	1	0	1	2	3	Would not try to get lots done
3. Did lots in a day	3	2	1	0	1	2	3	Did little in a day
4. Slowly got things done	3	2	1	0	1	2	3	Quickly got things done
5. Prided self on level of achievement	3	2	1	0	1	2	3	Not focussed on achieving
6. Would stop, rest and relax	3	2	1	0	1	2	3	Tended to 'push through' and not stop
7. Led a busy, active life	3	2	1	0	1	2	3	Was not busy or active
8. Put in minimal effort	3	2	1	0	1	2	3	Always put in 100% effort

2. Below are some statements about the way you may feel about having CFS. Please answer each statement according to the way you think **MOST OF THE TIME**.

	Totally agree	Agree very much	Agree slightly	Neutral	Dis-agree slightly	Dis-agree very much	Totally dis-agree
1. Activity makes me feel worse.	1	2	3	4	5	6	7
2. I can do things to the same standard as I used to.	1	2	3	4	5	6	7
3. I should strive to achieve my previous level of performance and activity.	1	2	3	4	5	6	7
4. Because of my illness I feel that I am being left behind.	1	2	3	4	5	6	7
5. I feel that it is important to be seen to cope.	1	2	3	4	5	6	7
6. I should rest as much as possible to get better.	1	2	3	4	5	6	7
7. People think I'm lazy if I don't achieve as much as I used to.	1	2	3	4	5	6	7
8. Through my illness I have discovered strengths in myself that I would not otherwise have seen.	1	2	3	4	5	6	7

3. Below are some statements about the way some people think. Please answer each statement according to the way you think **MOST OF THE TIME**.

	Totally agree	Agree very much	Agree slightly	Neutral	Dis-agree slightly	Dis-agree very much	Totally dis-agree
1. It is difficult to be happy, unless one is good looking, intelligent, rich and creative.	1	2	3	4	5	6	7
2. Happiness is more a matter of my attitude towards myself than the way other people feel about me.	1	2	3	4	5	6	7
3. People will probably think less of me if I make a mistake.	1	2	3	4	5	6	7
4. If I do not do well all the time, people will not respect me.	1	2	3	4	5	6	7
5. For me to show emotional distress is a sign of weakness.	1	2	3	4	5	6	7
6. Taking even a small risk is foolish, because the loss is likely to be a disaster.	1	2	3	4	5	6	7
7. If someone does a task at work/school better than I, then I feel like I failed the whole task.	1	2	3	4	5	6	7
8. It is possible to gain another person's respect without being especially talented at anything.	1	2	3	4	5	6	7
9. I need to achieve to be worthwhile.	1	2	3	4	5	6	7
10. I cannot be happy unless most people I know admire me.	1	2	3	4	5	6	7
11. If a person asks for help, it is a sign of weakness.	1	2	3	4	5	6	7
12. I hate being less than the best at things.	1	2	3	4	5	6	7
13. If I do not do as well as other people, it means I am an inferior human being.	1	2	3	4	5	6	7
14. If I fail at my work/school, then I am a failure as a person.	1	2	3	4	5	6	7
15. If you cannot do something well, there is little point in doing it at all.	1	2	3	4	5	6	7
16. Making mistakes is fine, because I can learn from them.	1	2	3	4	5	6	7
17. If someone disagrees with me, it probably indicates that he or she does not like me.	1	2	3	4	5	6	7

	Totally agree	Agree very much	Agree slightly	Neutral	Dis- agree slightly	Dis- agree very much	Totally dis- agree
18. I am inadequate if I don't try hard to cope.	1	2	3	4	5	6	7
19. The fewer mistakes I make, the more people will like me.	1	2	3	4	5	6	7
20. If I fail partly, it is as bad as being a complete failure.	1	2	3	4	5	6	7
21. If other people know what you are really like, they will think less of you.	1	2	3	4	5	6	7
22. Even when I do something very carefully, I often feel that it is not quite right.	1	2	3	4	5	6	7
23. I am nothing if a person I love doesn't love me.	1	2	3	4	5	6	7
24. One can get pleasure from an activity regardless of the end result.	1	2	3	4	5	6	7
25. People will only value me if I'm emotionally strong.	1	2	3	4	5	6	7
26. People should have a reasonable likelihood of success before undertaking anything.	1	2	3	4	5	6	7
27. I usually have doubts about the simple everyday things I do.	1	2	3	4	5	6	7
28. My value as a person depends greatly on what others think of me.	1	2	3	4	5	6	7
29. If I don't set the highest standards for myself, I am likely to end up a second rate person.	1	2	3	4	5	6	7
30. If I am a worthwhile person, I must be truly outstanding in at least one major respect.	1	2	3	4	5	6	7
31. People will only value me if I'm successful.	1	2	3	4	5	6	7
32. People who have good ideas are more worthy than those who do not.	1	2	3	4	5	6	7
33. I should be upset if I make a mistake.	1	2	3	4	5	6	7
34. My own opinions of myself are more important than others' opinions of me.	1	2	3	4	5	6	7
35. I tend to get behind in my work because I repeat things over and over.	1	2	3	4	5	6	7

	Totally agree	Agree very much	Agree slightly	Neutral	Dis- agree slightly	Dis- agree very much	Totally dis- agree
36. People will only value me if I'm cheerful.	1	2	3	4	5	6	7
37. To be a good, moral, worthwhile person, I must help everyone who needs it.	1	2	3	4	5	6	7
38. If I ask a question, it makes me look inferior.	1	2	3	4	5	6	7
39. It is awful to be disapproved of by people important to you.	1	2	3	4	5	6	7
40. It takes me a long time to get something "right".	1	2	3	4	5	6	7
41. If you don't have other people to lean on, you are bound to be sad.	1	2	3	4	5	6	7
42. I can reach important goals without slave driving myself.	1	2	3	4	5	6	7
43. It is possible for a person to be scolded and not get upset.	1	2	3	4	5	6	7
44. People will only value me if I'm well.	1	2	3	4	5	6	7
45. I can not trust other people because they might be cruel to me.	1	2	3	4	5	6	7
46. It is important to me that I be thoroughly competent in everything I do.	1	2	3	4	5	6	7
47. If others dislike you, you cannot be happy.	1	2	3	4	5	6	7
48. It is best to give up your own interests in order to please other people.	1	2	3	4	5	6	7
49. I set higher goals than most people.	1	2	3	4	5	6	7
50. My happiness depends more on other people than it does on me.	1	2	3	4	5	6	7
51. People will only value me if I'm coping with stress.	1	2	3	4	5	6	7
52. I do not need the approval of other people in order to be happy.	1	2	3	4	5	6	7
53. If a person avoids problems, the problems tend to go away.	1	2	3	4	5	6	7
54. I am very good at focussing my efforts on attaining a goal.	1	2	3	4	5	6	7
55. I can be happy even if I miss out on many of the good things in life.	1	2	3	4	5	6	7

	Totally agree	Agree very much	Agree slightly	Neutral	Dis- agree slightly	Dis- agree very much	Totally dis- agree
56. What other people think about me is very important.	1	2	3	4	5	6	7
57. Being isolated from others is bound to lead to unhappiness.	1	2	3	4	5	6	7
58. I have extremely high goals.	1	2	3	4	5	6	7
59. I can find happiness without being loved by another person.	1	2	3	4	5	6	7

4. Have you received any counselling support regarding having CFS? ☐ Yes ☐ No

5. If ‘yes’ who from (eg GP, rehabilitation worker, ME/CFS Society members, psychologist, social worker, clergy etc)?

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6. What counselling approaches have you found helpful or would find helpful in dealing with your illness?

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----- *Thankyou* for your time and your valuable assistance -----



PSYCHOLOGICAL SUPPORT IN CHRONIC FATIGUE SYNDROME

About This Study

This study is designed to help determine in which ways health professionals can provide psychological support to people with Chronic Fatigue Syndrome (CFS).

You may have been asked to complete this questionnaire because you have CFS; or because you have depression or are a healthy person whose information is needed as a comparison.

Participating in the study will involve completing the questionnaire and signing the attached consent form. Your signed consent is necessary to indicate your agreement to participate in the study. Although your signature appears on the consent form, it will be detached from the completed questionnaire before any data processing commences. In this way there will be no identifying information attached to any completed form, and thus anonymity and confidentiality is assured.

You may also wish to be informed of the outcome of the study and may wish to receive a summary of the results. If you do, please complete the slip indicating your interest. It similarly will not be retained with the completed questionnaire.

Instructions

1. Please sign the consent form.
2. Complete the questionnaire. If you need any assistance with completing the questionnaire, please contact me at the Psychology Department, ANU on phone 249 2795. If you find the questionnaire tiring, please have breaks and complete it in stages.
3. If you are interested in receiving feedback about the study, complete the interest in results form.
4. Return the consent form and questionnaire in the return envelope within a week or so of receiving the questionnaire. Also enclose the interest in results form if you wish.

Thankyou

I greatly appreciate your assistance and thank you most sincerely for your generosity in providing your time to complete the questionnaire. I trust that the results of this study will assist people with Chronic Fatigue Syndrome in the future.

Juanita Kolaric
Master of Clinical Psychology Student
Australian National University

Please return with the questionnaire:

CONSENT FORM

I understand the nature of the study and consent to completing the form. I am aware that I may withdraw this consent at any stage during the study.

Signature: _____

Date: ___/___/___

INTEREST IN RESULTS FORM
(Optional)

I am interested in receiving a summary of the results when the study is complete:

Name: _____

Address: _____

BACKGROUND INFORMATION

1. Age: _____

2. Sex: ☐ Male ☐ Female

Occupation

3. Are you currently doing paid work? ☐ Yes ☐ No

4. What is your usual occupation:

<input type="checkbox"/> Manager or administrator (eg general or specialist manager, farm manager)
<input type="checkbox"/> Professional (eg scientist, school teacher, building professional, health professional)
<input type="checkbox"/> Para-professional (eg technical officer, nurse, police officer)
<input type="checkbox"/> Tradesperson (eg electrical or building trades)
<input type="checkbox"/> Clerk (eg general clerk, stenographer or typist, receptionist)
<input type="checkbox"/> Salesperson or personal service worker (eg insurance, sales, real estate)
<input type="checkbox"/> Plant and machine operator or driver (eg road and rail transport driver, machine operator)
<input type="checkbox"/> Labourer or related worker (eg trades, factory hands, agricultural labourers, construction and mining labourers)
<input type="checkbox"/> Unpaid work (tick if have never done paid work, or if have not done paid work for 10 or more years)(eg home keeping)

Education

5. How old were you when you left school?

<input type="checkbox"/> Still at secondary school	<input type="checkbox"/> 16 years
<input type="checkbox"/> Did not go to school	<input type="checkbox"/> 17 years
<input type="checkbox"/> 14 years or younger	<input type="checkbox"/> 18 years
<input type="checkbox"/> 15 years	<input type="checkbox"/> 19 years or older

6. What is the highest qualification that you have attained since leaving school?

<input type="checkbox"/> Skilled vocational certificate	<input type="checkbox"/> Bachelor degree
<input type="checkbox"/> Basic vocational certificate	<input type="checkbox"/> Post graduate diploma
<input type="checkbox"/> Associate diploma	<input type="checkbox"/> Higher degree
<input type="checkbox"/> Undergraduate diploma	<input type="checkbox"/> Not applicable

Marital status

7. What is your present marital status?

<input type="checkbox"/> Never married	<input type="checkbox"/> Divorced
<input type="checkbox"/> Married/ defacto	<input type="checkbox"/> Widowed
<input type="checkbox"/> Separated but not divorced	

Sport

8. Have you are ever played sport at a highly competitive level (eg at State or National level)?

☐ Yes ☐ No

Background of Parents

9. What are your parents' usual occupations (if a parent is retired or deceased please indicate their previous occupation):

Father	Mother	Occupation
<input type="checkbox"/>	<input type="checkbox"/>	Manager or administrator (eg general or specialist manager, farm manager)
<input type="checkbox"/>	<input type="checkbox"/>	Professional (eg scientist, school teacher, building professional, health professional)
<input type="checkbox"/>	<input type="checkbox"/>	Para-professional (eg technical officer, nurse, police officer)
<input type="checkbox"/>	<input type="checkbox"/>	Tradesperson (eg electrical or building trades)
<input type="checkbox"/>	<input type="checkbox"/>	Clerk (eg general clerk, stenographer or typist, receptionist)
<input type="checkbox"/>	<input type="checkbox"/>	Salespersons and personal service workers (eg insurance, sales, real estate)
<input type="checkbox"/>	<input type="checkbox"/>	Plant and machine operator or driver (eg road and rail transport driver, machine operator)
<input type="checkbox"/>	<input type="checkbox"/>	Labourer or related worker (eg trades assistant, factory hand, agricultural, construction and mining labourer)
<input type="checkbox"/>	<input type="checkbox"/>	Unpaid work (eg home keeping)
<input type="checkbox"/>	<input type="checkbox"/>	Unknown

10. How old were your parents when they left school?

Father	Mother	
<input type="checkbox"/>	<input type="checkbox"/>	Did not go to school
<input type="checkbox"/>	<input type="checkbox"/>	14 years or younger
<input type="checkbox"/>	<input type="checkbox"/>	15 years
<input type="checkbox"/>	<input type="checkbox"/>	16 years
<input type="checkbox"/>	<input type="checkbox"/>	17 years
<input type="checkbox"/>	<input type="checkbox"/>	18 years
<input type="checkbox"/>	<input type="checkbox"/>	19 years or older
<input type="checkbox"/>	<input type="checkbox"/>	Don't know

11. What is the highest qualification that your parents attained since leaving school?

Father	Mother	
<input type="checkbox"/>	<input type="checkbox"/>	Basic vocational certificate
<input type="checkbox"/>	<input type="checkbox"/>	Skilled vocational certificate
<input type="checkbox"/>	<input type="checkbox"/>	Associate diploma
<input type="checkbox"/>	<input type="checkbox"/>	Undergraduate diploma
<input type="checkbox"/>	<input type="checkbox"/>	Bachelor degree
<input type="checkbox"/>	<input type="checkbox"/>	Post graduate diploma
<input type="checkbox"/>	<input type="checkbox"/>	Higher degree
<input type="checkbox"/>	<input type="checkbox"/>	Not applicable
<input type="checkbox"/>	<input type="checkbox"/>	Don't know

DETAILS OF ILLNESS

1. During the **LAST MONTH** have you suffered from (please circle a number for each symptom):

	never	occasionally	frequently	everyday
1. Muscle weakness	0	1	2	3
2. Muscle pain/ discomfort	0	1	2	3
3. Fatigue after exercise lasting more than one day	0	1	2	3
4. Feeling physically tired and drained even after resting	0	1	2	3
5. Being noticeably slowed down	0	1	2	3
6. Noticeable agitation or restlessness	0	1	2	3
7. Chills or mild fever	0	1	2	3
8. Sore throat	0	1	2	3
9. Swollen glands	0	1	2	3
10. Headaches	0	1	2	3
11. Joint pains	0	1	2	3
12. Irritation by light	0	1	2	3
13. Blurred or double vision	0	1	2	3
14. Forgetfulness	0	1	2	3
15. Irritability	0	1	2	3
16. Confusion	0	1	2	3
17. Inability to think clearly	0	1	2	3
18. Inability to concentrate	0	1	2	3
19. Depressed mood	0	1	2	3
20. Feeling worthless	0	1	2	3
21. General feelings of guilt	0	1	2	3
22. Feeling the future is bleak	0	1	2	3
23. Recurrent thoughts of death	0	1	2	3
24. Lack of interest or pleasure in most activities	0	1	2	3
25. Inability to sleep	0	1	2	3
26. Sleeping too much	0	1	2	3
27. Reduced appetite	0	1	2	3
28. _____ (other - please specify)	0	1	2	3

2. Which year did a doctor first diagnose your depression? 19__

3. How long have you been ill with depression? __ yrs __ mths

4. What stage of the depression do you consider that you are at?

- ☐ Beginning
- ☐ In its midst
- ☐ Recovery
- ☐ Don't know

5. Is your condition:

<input type="checkbox"/> definitely physical
<input type="checkbox"/> physical but psychological factors have some importance
<input type="checkbox"/> equally physical and psychological
<input type="checkbox"/> mainly psychological
<input type="checkbox"/> don't know

6. In which year was the worst month of your depression (ie when has it been its worst so far)?
19__

7. How critical of you were the following people during that worst month of having depression?
(Please circle a number for each person(s))

	not at all critical	a little critical	quite critical	very critical	not relevant
1. Partner	0	1	2	3	4
2. Mother	0	1	2	3	4
3. Father	0	1	2	3	4
4. Own children	0	1	2	3	4
5. Other family members	0	1	2	3	4
6. Friends	0	1	2	3	4
7. Colleagues	0	1	2	3	4
8. Doctors	0	1	2	3	4
9. Acquaintances	0	1	2	3	4
10. Yourself	0	1	2	3	4

8. How supportive of you were the following people during that worst month of having depression?

	completely un- supportive	a little supportive	quite supportive	very supportive	not relevant
1. Partner	0	1	2	3	4
2. Mother	0	1	2	3	4
3. Father	0	1	2	3	4
4. Own children	0	1	2	3	4
5. Other family members	0	1	2	3	4
6. Friends	0	1	2	3	4
7. Colleagues	0	1	2	3	4
8. Doctors	0	1	2	3	4
9. Acquaintances	0	1	2	3	4
10. Yourself	0	1	2	3	4

9. During the **LAST MONTH**, how much has having depression affected you in the following areas (please circle the appropriate number):

<u>Family/home management</u> This category refers to activities related to the home or family. It includes chores or duties performed in and around the house and errands or favours for other family members (eg driving children to school)	0 not at all	1	2	3	4	5	6	7	8 very severely - cannot do it
<u>Ability to work</u> This category refers to activities that are part of or directly related to one's job. This includes non-paying jobs as well, such as that of home-maker or volunteer worker, and activities as a student	0 not at all	1	2	3	4	5	6	7	8 very severely - cannot do it
<u>Self-care</u> This category includes activities which involve personal maintenance and independent daily living (eg taking a shower, getting dressed, driving oneself etc)	0 not at all	1	2	3	4	5	6	7	8 very severely - cannot do it
<u>Social Leisure</u> This category refers to activities which involve participation with friends and acquaintances and family members outside your home. It includes parties, theatre, concerts, dining out, meeting with friends at home or out, and other social functions	0 not at all	1	2	3	4	5	6	7	8 very severely - cannot do it
<u>Private Leisure</u> This category includes hobbies, sports and other leisure time activities	0 not at all	1	2	3	4	5	6	7	8 very severely - cannot do it

10. Feelings play an important part in most illnesses. Following are 14 questions which relate to how you feel. Read each item and circle the reply which comes closest to how you have been feeling in the **PAST WEEK**. Your immediate reaction is usually accurate so there is no need to take too long over your responses.

A. I feel tense or 'wound up'

- ③ Most of the time
- ② A lot of the time
- ① From time to time, occasionally
- ④ Not at all

B. I still enjoy the things I used to enjoy

- ④ Definitely as much
- ① Not quite so much
- ② Only a little
- ③ Hardly at all

C. I get sort of frightened feeling as if something awful is about to happen

- ③ Very definitely and quite badly
- ② Yes, but not too badly
- ① A little, but it doesn't worry me
- ④ Not at all

D. I can laugh and see the funny side of things

- ④ As much as I always could
- ① Not quite so much now
- ② Definitely not so much now
- ③ Not at all

E. Worrying thoughts go through my mind

- ③ A great deal of the time
- ② A lot of the time
- ① Not too often
- ④ Very little

F. I feel cheerful

- ③ Never
- ② Not often
- ① Sometimes
- ④ Most of the time

G. I can sit at ease and feel relaxed

- ④ Definitely
- ① Usually
- ② Not often
- ③ Not at all

H. I feel as if I am slowed down

- Nearly all the time ③
- very often ②
- Sometimes ①
- Not at all ④

I. I get a sort of frightened feeling like 'butterflies' in the stomach

- Not at all ④
- Occasionally ①
- Quite often ②
- Very often ③

J. I have lost interest in my appearance

- Definitely ③
- I don't take as much care as I should ②
- I may not take quite as much care ①
- I take just as much care as ever ④

K. I feel restless as if I have to be on the move

- Very much indeed ③
- Quite a lot ②
- Not very much ①
- Not at all ④

L. I look forward with enjoyment to things

- As much as I ever did ④
- Rather less than I used to ①
- Definitely less than I used to ②
- Hardly at all ③

M. I get sudden feelings of panic

- Very often indeed ③
- Quite often ②
- Not very often ①
- Not at all ④

N. I can enjoy a good book or radio or television programme

- Often ④
- Sometimes ①
- Not often ②
- Very seldom ③

APPROACH AND ATTITUDES

1. How would you describe your style of behaviour **PRIOR** to developing depression?
(Decide which of the two opposite descriptions you agree with and then indicate how strongly you agree by circling the appropriate number. If you do not agree with either, circle '0'. Eg If you thought that before your illness you were rushed often but not always, you would circle;

1. Never rushed 3 2 1 0 1 (2) 3 Always rushed)

1. Never rushed	3	2	1	0	1	2	3	Always rushed
2. Would go 'all out' to get things done	3	2	1	0	1	2	3	Would not try to get lots done
3. Did lots in a day	3	2	1	0	1	2	3	Did little in a day
4. Slowly got things done	3	2	1	0	1	2	3	Quickly got things done
5. Prided self on level of achievement	3	2	1	0	1	2	3	Not focussed on achieving
6. Would stop, rest and relax	3	2	1	0	1	2	3	Tended to 'push through' and not stop
7. Led a busy, active life	3	2	1	0	1	2	3	Was not busy or active
8. Put in minimal effort	3	2	1	0	1	2	3	Always put in 100% effort

2. Below are some statements about the way you may feel about your depression. Please answer each statement according to the way you think **MOST OF THE TIME**.

	Totally agree	Agree very much	Agree slightly	Neutral	Dis-agree slightly	Dis-agree very much	Totally dis-agree
1. Activity makes me feel worse.	1	2	3	4	5	6	7
2. I can do things to the same standard as I used to.	1	2	3	4	5	6	7
3. I should strive to achieve my previous level of performance and activity.	1	2	3	4	5	6	7
4. Because of my illness I feel that I am being left behind.	1	2	3	4	5	6	7
5. I feel that it is important to be seen to cope.	1	2	3	4	5	6	7
6. I should rest as much as possible to get better.	1	2	3	4	5	6	7
7. People think I'm lazy if I don't achieve as much as I used to.	1	2	3	4	5	6	7
8. Through my illness I have discovered strengths in myself that I would not otherwise have seen.	1	2	3	4	5	6	7

3. Below are some statements about the way some people think. Please answer each statement according to the way you think **MOST OF THE TIME**.

	Totally agree	Agree very much	Agree slightly	Neutral	Dis- agree slightly	Dis- agree very much	Totally dis- agree
1. It is difficult to be happy, unless one is good looking, intelligent, rich and creative.	1	2	3	4	5	6	7
2. Happiness is more a matter of my attitude towards myself than the way other people feel about me.	1	2	3	4	5	6	7
3. People will probably think less of me if I make a mistake.	1	2	3	4	5	6	7
4. If I do not do well all the time, people will not respect me.	1	2	3	4	5	6	7
5. For me to show emotional distress is a sign of weakness.	1	2	3	4	5	6	7
6. Taking even a small risk is foolish, because the loss is likely to be a disaster.	1	2	3	4	5	6	7
7. If someone does a task at work/school better than I, then I feel like I failed the whole task.	1	2	3	4	5	6	7
8. It is possible to gain another person's respect without being especially talented at anything.	1	2	3	4	5	6	7
9. I need to achieve to be worthwhile.	1	2	3	4	5	6	7
10. I cannot be happy unless most people I know admire me.	1	2	3	4	5	6	7
11. If a person asks for help, it is a sign of weakness.	1	2	3	4	5	6	7
12. I hate being less than the best at things.	1	2	3	4	5	6	7
13. If I do not do as well as other people, it means I am an inferior human being.	1	2	3	4	5	6	7
14. If I fail at my work/school, then I am a failure as a person.	1	2	3	4	5	6	7
15. If you cannot do something well, there is little point in doing it at all.	1	2	3	4	5	6	7
16. Making mistakes is fine, because I can learn from them.	1	2	3	4	5	6	7
17. If someone disagrees with me, it probably indicates that he or she does not like me.	1	2	3	4	5	6	7

	Totally agree	Agree very much	Agree slightly	Neutral	Dis- agree slightly	Dis- agree very much	Totally dis- agree
18. I am inadequate if I don't try hard to cope.	1	2	3	4	5	6	7
19. The fewer mistakes I make, the more people will like me.	1	2	3	4	5	6	7
20. If I fail partly, it is as bad as being a complete failure.	1	2	3	4	5	6	7
21. If other people know what you are really like, they will think less of you.	1	2	3	4	5	6	7
22. Even when I do something very carefully, I often feel that it is not quite right.	1	2	3	4	5	6	7
23. I am nothing if a person I love doesn't love me.	1	2	3	4	5	6	7
24. One can get pleasure from an activity regardless of the end result.	1	2	3	4	5	6	7
25. People will only value me if I'm emotionally strong.	1	2	3	4	5	6	7
26. People should have a reasonable likelihood of success before undertaking anything.	1	2	3	4	5	6	7
27. I usually have doubts about the simple everyday things I do.	1	2	3	4	5	6	7
28. My value as a person depends greatly on what others think of me.	1	2	3	4	5	6	7
29. If I don't set the highest standards for myself, I am likely to end up a second rate person.	1	2	3	4	5	6	7
30. If I am a worthwhile person, I must be truly outstanding in at least one major respect.	1	2	3	4	5	6	7
31. People will only value me if I'm successful.	1	2	3	4	5	6	7
32. People who have good ideas are more worthy than those who do not.	1	2	3	4	5	6	7
33. I should be upset if I make a mistake.	1	2	3	4	5	6	7
34. My own opinions of myself are more important than others' opinions of me.	1	2	3	4	5	6	7
35. I tend to get behind in my work because I repeat things over and over.	1	2	3	4	5	6	7

	Totally agree	Agree very much	Agree slightly	Neutral	Dis- agree slightly	Dis- agree very much	Totally dis- agree
36. People will only value me if I'm cheerful.	1	2	3	4	5	6	7
37. To be a good, moral, worthwhile person, I must help everyone who needs it.	1	2	3	4	5	6	7
38. If I ask a question, it makes me look inferior.	1	2	3	4	5	6	7
39. It is awful to be disapproved of by people important to you.	1	2	3	4	5	6	7
40. It takes me a long time to get something "right".	1	2	3	4	5	6	7
41. If you don't have other people to lean on, you are bound to be sad.	1	2	3	4	5	6	7
42. I can reach important goals without slave driving myself.	1	2	3	4	5	6	7
43. It is possible for a person to be scolded and not get upset.	1	2	3	4	5	6	7
44. People will only value me if I'm well.	1	2	3	4	5	6	7
45. I can not trust other people because they might be cruel to me.	1	2	3	4	5	6	7
46. It is important to me that I be thoroughly competent in everything I do.	1	2	3	4	5	6	7
47. If others dislike you, you cannot be happy.	1	2	3	4	5	6	7
48. It is best to give up your own interests in order to please other people.	1	2	3	4	5	6	7
49. I set higher goals than most people.	1	2	3	4	5	6	7
50. My happiness depends more on other people than it does on me.	1	2	3	4	5	6	7
51. People will only value me if I'm coping with stress.	1	2	3	4	5	6	7
52. I do not need the approval of other people in order to be happy.	1	2	3	4	5	6	7
53. If a person avoids problems, the problems tend to go away.	1	2	3	4	5	6	7
54. I am very good at focussing my efforts on attaining a goal.	1	2	3	4	5	6	7
55. I can be happy even if I miss out on many of the good things in life.	1	2	3	4	5	6	7

	Totally agree	Agree very much	Agree slightly	Neutral	Dis- agree slightly	Dis- agree very much	Totally dis- agree
56. What other people think about me is very important.	1	2	3	4	5	6	7
57. Being isolated from others is bound to lead to unhappiness.	1	2	3	4	5	6	7
58. I have extremely high goals.	1	2	3	4	5	6	7
59. I can find happiness without being loved by another person.	1	2	3	4	5	6	7

4. Have you received any counselling support regarding your depression? ☐ Yes ☐ No

5. If 'yes' who from (eg GP, rehabilitation worker, psychologist, social worker, clergy etc)?

.....

6. What counselling approaches have you found helpful or would find helpful in dealing with your illness?

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----- *Thankyou* for your time and your valuable assistance -----

Australian National University



PSYCHOLOGICAL SUPPORT IN CHRONIC FATIGUE SYNDROME

About This Study

This study is designed to help determine in which ways health professionals can provide psychological support to people with Chronic Fatigue Syndrome (CFS).

You may have been asked to complete this questionnaire because you have CFS; or because you have depression or are a healthy person whose information is needed as a comparison.

Participating in the study will involve completing the questionnaire and signing the attached consent form. Your signed consent is necessary to indicate your agreement to participate in the study. Although your signature appears on the consent form, it will be detached from the completed questionnaire before any data processing commences. In this way there will be no identifying information attached to any completed form, and thus anonymity and confidentiality is assured.

You may also wish to be informed of the outcome of the study and may wish to receive a summary of the results. If you do, please complete the slip indicating your interest. It similarly will not be retained with the completed questionnaire.

Instructions

1. Please sign the consent form.
2. Complete the questionnaire. If you need any assistance with completing the questionnaire, please contact me at the Psychology Department, ANU on phone 249 2795. If you find the questionnaire tiring, please have breaks and complete it in stages.
3. If you are interested in receiving feedback about the study, complete the interest in results form.
4. Return the consent form and questionnaire in the return envelope within a week or so of receiving the questionnaire. Also enclose the interest in results form if you wish.

Thankyou

I greatly appreciate your assistance and thank you most sincerely for your generosity in providing your time to complete the questionnaire. I trust that the results of this study will assist people with Chronic Fatigue Syndrome in the future.

Juanita Kolaric
Master of Clinical Psychology Student
Australian National University

Please return with the questionnaire:

CONSENT FORM

I understand the nature of the study and consent to completing the form. I am aware that I may withdraw this consent at any stage during the study.

Signature: _____

Date: ___/___/___

INTEREST IN RESULTS FORM
(Optional)

I am interested in receiving a summary of the results when the study is complete:

Name: _____

Address: _____

BACKGROUND INFORMATION

1. Age: _____

2. Sex: ☐ Male ☐ Female

Occupation

3. Are you currently doing paid work? ☐ Yes ☐ No

4. What is your usual occupation:

<input type="checkbox"/> Manager or administrator (eg general or specialist manager, farm manager)
<input type="checkbox"/> Professional (eg scientist, school teacher, building professional, health professional)
<input type="checkbox"/> Para-professional (eg technical officer, nurse, police officer)
<input type="checkbox"/> Tradesperson (eg electrical or building trades)
<input type="checkbox"/> Clerk (eg general clerk, stenographer or typist, receptionist)
<input type="checkbox"/> Salesperson or personal service worker (eg insurance, sales, real estate)
<input type="checkbox"/> Plant and machine operator or driver (eg road and rail transport driver, machine operator)
<input type="checkbox"/> Labourer or related worker (eg trades, factory hands, agricultural labourers, construction and mining labourers)
<input type="checkbox"/> Unpaid work (tick if have never done paid work, or if have not done paid work for 10 or more years)(eg home keeping)

Education

5. How old were you when you left school?

<input type="checkbox"/> Still at secondary school	<input type="checkbox"/> 16 years
<input type="checkbox"/> Did not go to school	<input type="checkbox"/> 17 years
<input type="checkbox"/> 14 years or younger	<input type="checkbox"/> 18 years
<input type="checkbox"/> 15 years	<input type="checkbox"/> 19 years or older

6. What is the highest qualification that you have attained since leaving school?

<input type="checkbox"/> Skilled vocational certificate	<input type="checkbox"/> Bachelor degree
<input type="checkbox"/> Basic vocational certificate	<input type="checkbox"/> Post graduate diploma
<input type="checkbox"/> Associate diploma	<input type="checkbox"/> Higher degree
<input type="checkbox"/> Undergraduate diploma	<input type="checkbox"/> Not applicable

Marital status

7. What is your present marital status?

<input type="checkbox"/> Never married	<input type="checkbox"/> Divorced
<input type="checkbox"/> Married/ defacto	<input type="checkbox"/> Widowed
<input type="checkbox"/> Separated but not divorced	

Sport

8. Have you are ever played sport at a highly competitive level (eg at State or National level)?

☐ Yes ☐ No

Background of Parents

9. What are your parents' usual occupations (if a parent is retired or deceased please indicate their previous occupation):

Father	Mother	Occupation
<input type="checkbox"/>	<input type="checkbox"/>	Manager or administrator (eg general or specialist manager, farm manager)
<input type="checkbox"/>	<input type="checkbox"/>	Professional (eg scientist, school teacher, building professional, health professional)
<input type="checkbox"/>	<input type="checkbox"/>	Para-professional (eg technical officer, nurse, police officer)
<input type="checkbox"/>	<input type="checkbox"/>	Tradesperson (eg electrical or building trades)
<input type="checkbox"/>	<input type="checkbox"/>	Clerk (eg general clerk, stenographer or typist, receptionist)
<input type="checkbox"/>	<input type="checkbox"/>	Salespersons and personal service workers (eg insurance, sales, real estate)
<input type="checkbox"/>	<input type="checkbox"/>	Plant and machine operator or driver (eg road and rail transport driver, machine operator)
<input type="checkbox"/>	<input type="checkbox"/>	Labourer or related worker (eg trades assistant, factory hand, agricultural, construction and mining labourer)
<input type="checkbox"/>	<input type="checkbox"/>	Unpaid work (eg home keeping)
<input type="checkbox"/>	<input type="checkbox"/>	Unknown

10. How old were your parents when they left school?

Father	Mother	
<input type="checkbox"/>	<input type="checkbox"/>	Did not go to school
<input type="checkbox"/>	<input type="checkbox"/>	14 years or younger
<input type="checkbox"/>	<input type="checkbox"/>	15 years
<input type="checkbox"/>	<input type="checkbox"/>	16 years
<input type="checkbox"/>	<input type="checkbox"/>	17 years
<input type="checkbox"/>	<input type="checkbox"/>	18 years
<input type="checkbox"/>	<input type="checkbox"/>	19 years or older
<input type="checkbox"/>	<input type="checkbox"/>	Don't know

11. What is the highest qualification that your parents attained since leaving school?

Father	Mother	
<input type="checkbox"/>	<input type="checkbox"/>	Basic vocational certificate
<input type="checkbox"/>	<input type="checkbox"/>	Skilled vocational certificate
<input type="checkbox"/>	<input type="checkbox"/>	Associate diploma
<input type="checkbox"/>	<input type="checkbox"/>	Undergraduate diploma
<input type="checkbox"/>	<input type="checkbox"/>	Bachelor degree
<input type="checkbox"/>	<input type="checkbox"/>	Post graduate diploma
<input type="checkbox"/>	<input type="checkbox"/>	Higher degree
<input type="checkbox"/>	<input type="checkbox"/>	Not applicable
<input type="checkbox"/>	<input type="checkbox"/>	Don't know

DETAILS OF ANY ILLNESS

1. During the **LAST MONTH** have you suffered from (please circle a number for each symptom):

	never	occasionally	frequently	everyday
1. Muscle weakness	0	1	2	3
2. Muscle pain/ discomfort	0	1	2	3
3. Fatigue after exercise lasting more than one day	0	1	2	3
4. Feeling physically tired and drained even after resting	0	1	2	3
5. Being noticeably slowed down	0	1	2	3
6. Noticeable agitation or restlessness	0	1	2	3
7. Chills or mild fever	0	1	2	3
8. Sore throat	0	1	2	3
9. Swollen glands	0	1	2	3
10. Headaches	0	1	2	3
11. Joint pains	0	1	2	3
12. Irritation by light	0	1	2	3
13. Blurred or double vision	0	1	2	3
14. Forgetfulness	0	1	2	3
15. Irritability	0	1	2	3
16. Confusion	0	1	2	3
17. Inability to think clearly	0	1	2	3
18. Inability to concentrate	0	1	2	3
19. Depressed mood	0	1	2	3
20. Feeling worthless	0	1	2	3
21. General feelings of guilt	0	1	2	3
22. Feeling the future is bleak	0	1	2	3
23. Recurrent thoughts of death	0	1	2	3
24. Lack of interest or pleasure in most activities	0	1	2	3
25. Inability to sleep	0	1	2	3
26. Sleeping too much	0	1	2	3
27. Reduced appetite	0	1	2	3
28. _____ (other - please specify)	0	1	2	3

2. Following are 14 questions which relate to how you feel. Read each item and circle the reply which comes closest to how you have been feeling in the **PAST WEEK**. Your immediate reaction is usually accurate so there is no need to take too long over your responses.
- A. I feel tense or 'wound up'**

③ Most of the time

② A lot of the time

① From time to time, occasionally

④ Not at all

B. I still enjoy the things I used to enjoy

④ Definitely as much

① Not quite so much

② Only a little

③ Hardly at all

C. I get sort of frightened feeling as if something awful is about to happen

③ Very definitely and quite badly

② Yes, but not too badly

① A little, but it doesn't worry me

④ Not at all

D. I can laugh and see the funny side of things

④ As much as I always could

① Not quite so much now

② Definitely not so much now

③ Not at all

E. Worrying thoughts go through my mind

③ A great deal of the time

② A lot of the time

① Not too often

④ Very little

F. I feel cheerful

③ Never

② Not often

① Sometimes

④ Most of the time

G. I can sit at ease and feel relaxed

④ Definitely

① Usually

② Not often

③ Not at all

H. I feel as if I am slowed down

Nearly all the time ③

very often ②

Sometimes ①

Not at all ④

I. I get a sort of frightened feeling like 'butterflies' in the stomach

Not at all ④

Occasionally ①

Quite often ②

Very often ③

J. I have lost interest in my appearance

Definitely ③

I don't take as much care as I should ②

I may not take quite as much care ①

I take just as much care as ever ④

K. I feel restless as if I have to be on the move

Very much indeed ③

Quite a lot ②

Not very much ①

Not at all ④

L. I look forward with enjoyment to things

As much as I ever did ④

Rather less than I used to ①

Definitely less than I used to ②

Hardly at all ③

M. I get sudden feelings of panic

Very often indeed ③

Quite often ②

Not very often ①

Not at all ④

N. I can enjoy a good book or radio or television programme

Often ④

Sometimes ①

Not often ②

Very seldom ③

APPROACH AND ATTITUDES

1. How would you describe your style of behaviour?

(Decide which of the two opposite descriptions you agree with and then indicate how strongly you agree by circling the appropriate number. If you do not agree with either, circle '0'. Eg If you think that you rush often but not always, you would circle:

1. *Never rushed*

$$3 \quad 2 \quad 1 \quad 0 \quad 1 \quad \textcircled{2} \quad 3$$

Always rushed)

1. Never rushed	3	2	1	0	1	2	3	Always rushed
2. Go 'all out' to get things done	3	2	1	0	1	2	3	Do not try to get lots done
3. Do lots in a day	3	2	1	0	1	2	3	Do little in a day
4. Slowly get things done	3	2	1	0	1	2	3	Quickly get things done
5. Pride self on level of achievement	3	2	1	0	1	2	3	Not focussed on achieving
6. Tend to stop, rest and relax	3	2	1	0	1	2	3	Tend to 'push through' and not stop
7. Lead a busy, active life	3	2	1	0	1	2	3	Am not busy or active
8. Put in minimal effort	3	2	1	0	1	2	3	Always put in 100% effort

2. Below are some statements about the way some people think. Please answer each statement according to the way you think **MOST OF THE TIME**.

	Totally agree	Agree very much	Agree slightly	Neutral	Dis-agree slightly	Dis-agree very much	Totally dis-agree
1. It is difficult to be happy, unless one is good looking, intelligent, rich and creative.	1	2	3	4	5	6	7
2. Happiness is more a matter of my attitude towards myself than the way other people feel about me.	1	2	3	4	5	6	7
3. People will probably think less of me if I make a mistake.	1	2	3	4	5	6	7
4. If I do not do well all the time, people will not respect me.	1	2	3	4	5	6	7
5. For me to show emotional distress is a sign of weakness.	1	2	3	4	5	6	7
6. Taking even a small risk is foolish, because the loss is likely to be a disaster.	1	2	3	4	5	6	7
7. If someone does a task at work/school better than I, then I feel like I failed the whole task.	1	2	3	4	5	6	7

	Totally agree	Agree very much	Agree slightly	Neutral	Dis- agree slightly	Dis- agree very much	Totally dis- agree
8. It is possible to gain another person's respect without being especially talented at anything.	1	2	3	4	5	6	7
9. I need to achieve to be worthwhile.	1	2	3	4	5	6	7
10. I cannot be happy unless most people I know admire me.	1	2	3	4	5	6	7
11. If a person asks for help, it is a sign of weakness.	1	2	3	4	5	6	7
12. I hate being less than the best at things.	1	2	3	4	5	6	7
13. If I do not do as well as other people, it means I am an inferior human being.	1	2	3	4	5	6	7
14. If I fail at my work/school, then I am a failure as a person.	1	2	3	4	5	6	7
15. If you cannot do something well, there is little point in doing it at all.	1	2	3	4	5	6	7
16. Making mistakes is fine, because I can learn from them.	1	2	3	4	5	6	7
17. If someone disagrees with me, it probably indicates that he or she does not like me.	1	2	3	4	5	6	7
18. I am inadequate if I don't try hard to cope.	1	2	3	4	5	6	7
19. The fewer mistakes I make, the more people will like me.	1	2	3	4	5	6	7
20. If I fail partly, it is as bad as being a complete failure.	1	2	3	4	5	6	7
21. If other people know what you are really like, they will think less of you.	1	2	3	4	5	6	7
22. Even when I do something very carefully, I often feel that it is not quite right.	1	2	3	4	5	6	7
23. I am nothing if a person I love doesn't love me.	1	2	3	4	5	6	7
24. One can get pleasure from an activity regardless of the end result.	1	2	3	4	5	6	7
25. People will only value me if I'm emotionally strong.	1	2	3	4	5	6	7
26. People should have a reasonable likelihood of success before undertaking anything.	1	2	3	4	5	6	7

	Totally agree	Agree very much	Agree slightly	Neutral	Dis- agree slightly	Dis- agree very much	Totally dis- agree
27. I usually have doubts about the simple everyday things I do.	1	2	3	4	5	6	7
28. My value as a person depends greatly on what others think of me.	1	2	3	4	5	6	7
29. If I don't set the highest standards for myself, I am likely to end up a second rate person.	1	2	3	4	5	6	7
30. If I am a worthwhile person, I must be truly outstanding in at least one major respect.	1	2	3	4	5	6	7
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32. People who have good ideas are more worthy than those who do not.	1	2	3	4	5	6	7
33. I should be upset if I make a mistake.	1	2	3	4	5	6	7
34. My own opinions of myself are more important than others' opinions of me.	1	2	3	4	5	6	7
35. I tend to get behind in my work because I repeat things over and over.	1	2	3	4	5	6	7
36. People will only value me if I'm cheerful.	1	2	3	4	5	6	7
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38. If I ask a question, it makes me look inferior.	1	2	3	4	5	6	7
39. It is awful to be disapproved of by people important to you.	1	2	3	4	5	6	7
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41. If you don't have other people to lean on, you are bound to be sad.	1	2	3	4	5	6	7
42. I can reach important goals without slave driving myself.	1	2	3	4	5	6	7
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45. I can not trust other people because they might be cruel to me.	1	2	3	4	5	6	7

	Totally agree	Agree very much	Agree slightly	Neutral	Dis- agree slightly	Dis- agree very much	Totally dis- agree
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49. I set higher goals than most people.	1	2	3	4	5	6	7
50. My happiness depends more on other people than it does on me.	1	2	3	4	5	6	7
51. People will only value me if I'm coping with stress.	1	2	3	4	5	6	7
52. I do not need the approval of other people in order to be happy.	1	2	3	4	5	6	7
53. If a person avoids problems, the problems tend to go away.	1	2	3	4	5	6	7
54. I am very good at focussing my efforts on attaining a goal.	1	2	3	4	5	6	7
55. I can be happy even if I miss out on many of the good things in life.	1	2	3	4	5	6	7
56. What other people think about me is very important.	1	2	3	4	5	6	7
57. Being isolated from others is bound to lead to unhappiness.	1	2	3	4	5	6	7
58. I have extremely high goals.	1	2	3	4	5	6	7
59. I can find happiness without being loved by another person.	1	2	3	4	5	6	7

----- Thankyou for your time and your valuable assistance -----

Dear Dr

INFORMATION FOR DOCTORS RE CFS RESEARCH

Firstly, a very big thankyou for agreeing to be involved in this research into Chronic Fatigue Syndrome (CFS).

I have attached (Attachment 1) another copy of the leaflet I sent to you as it provides an outline of the research being undertaken. In short, questionnaires have been developed to be completed by patients with CFS, and by two control groups - those with depression and those who are 'healthy'. As you would be aware, it is important for analysis that I have as large a sample as is possible and would therefore encourage you to include as many of your patients with CFS and depression as you can conveniently access; the 'healthy' group needs to be roughly comparable in size.

The steps involved are as follows:

1. Identify your patients with CFS and depression. The diagnostic criteria being used in the research are at Attachment 2. Check that your patients meet these criteria.
2. Do the same for a sample of patients identified as 'healthy' - the number should be about the same size as the largest of the other two groups. For example if you had seven depressed patients and five with CFS, you would send about seven to 'healthy' patients. (While I will do statistical analysis to check and control for differences in demographic characteristics between the groups, it would be helpful if the 'healthy' group were roughly comparable to the other groups in terms of sex, age and educational level).
3. Complete the details on the 'Basic Demographic Details of those Approached With Questionnaire' sheet (Attachment 3).
4. Either personally hand out or post the appropriate questionnaire to patients with CFS, depression, or who are 'healthy', using the envelopes provided. Please note that there are different questionnaires for each group. You may wish to sign or stamp the brief covering slip which I have prepared on your behalf.
5. Phone me when you have completed the demographic details and sent out the questionnaires - I will collect the details sheet and any unused materials.

Again many thanks and please do not hesitate to call me on 2302228 if you have any queries or if I can assist in any way.

Yours sincerely

Juanita Kolaric

The Australian National University



RESEARCH INTO CHRONIC FATIGUE SYNDROME

- Your help is required
- The demands on your time would be minimal (minutes) but your role vital
- You could help provide a better knowledge base for treatment
- Read on and please complete the attached return slip

Dear Doctor

I am writing to invite you to participate in some research on Chronic Fatigue Syndrome (CFS). I am conducting the research as a component of a Masters Degree in Clinical Psychology that I am currently undertaking at the ANU.

The thrust of the research is to examine whether there is a role for psychological treatment such as cognitive behaviour therapy in the treatment of CFS. As you would be aware, cognitive and behavioural approaches are used successfully in ameliorating the symptoms of chronic pain, depression and anxiety disorders; and cognitions have been found to be significant in predicting illness outcome in a variety of illnesses including coronary heart disease, rheumatoid arthritis, cancer, dermatitis and asthma.

Given the great demands on your time your foremost thought is probably that you do not have the time to participate. The demands of this study on your time would be minimal, while your role would be vital.

The study will involve sending questionnaires to patients identified as experiencing CFS as well as to two control groups - patients with depression and a 'healthy' group. The patients would, of course, be given the choice of participating or not.

Confidentiality of patients would also be maintained. Questionnaire responses would be anonymous and *your input would be sought, firstly in identifying your patients who met the diagnostic criteria, and secondly, in handing out or addressing the questionnaire envelopes* (again, to ensure confidentiality).

The study has the sanction of the Australian National University Ethics in Human Experimentation Committee.

The study subjects will be provided with background information about the study; will be invited to contact myself if they have any specific questions; and will also be invited to indicate on the questionnaire if they would be interested in obtaining feedback about the research results when the study is complete. I anticipate that I will commence data collection during November of this year.

Incidence studies suggest that the number of people experiencing CFS is small and spread out throughout general practice and relevant specialties (particularly in Canberra where there is no tertiary referral centre). Accordingly, it is critical for my research that I gain access to as many of these individuals as possible.

Please note that if you do not have patients with CFS, it is vital for the research that I also include a comparable number of subjects with clinical levels of depression and would still greatly value your input in gaining access to these people.

I can only complete this research with the assistance of health professionals like yourself. While there has been some research into the psychological aspects of CFS, there has been negligible research into the efficacy of psychological treatment in ameliorating symptoms of CFS, or in assisting with coping with this disabling illness.

I look forward to your reply - please do not hesitate to phone if you would like to obtain any further information (ph 2302228). Please respond with the attached slip.

Return to:

*Juanita Kolaric
Psychology Department
Australian National
University
ACT 0200*

- ☐ I am interested in participating in the research into Chronic Fatigue Syndrome (but reserve the right to withdraw at any time)
- ☐ I do not wish to be involved in the research into Chronic Fatigue Syndrome

Name:

.....

Address:

.....

.....

Phone:

.....

CRITERIA FOR DIAGNOSIS OF CHRONIC FATIGUE SYNDROME

(Based on the criteria developed by the International CFS Study Group -
Annals of Internal Medicine, 1994)

1. Fatigue.
2. Symptoms persistent or recurrent during six or more consecutive months and not predating the fatigue.
3. Four or more of the following symptoms:
 - self reported impairment in short term memory (severe enough to cause substantial reduction in previous levels of occupational, educational, social or personal activities)
 - sore throat
 - tender cervical or axillary lymph nodes
 - muscle pain, multijoint pain with or without joint swelling or redness
 - headaches of a new type, pattern or severity
 - unrefreshing sleep
 - post-exertional malaise of more than 24 hours

Diagnosis is **excluded** if there is:

1. Any active medical condition that can explain the presence of chronic fatigue such as untreated hypothyroidism, sleep apnea and narcolepsy, and iatrogenic conditions such as side effects of medication.
2. Any previously diagnosed medical condition whose resolution has not been documented beyond reasonable doubt and whose continued activity may explain the chronic fatiguing illness. Such conditions may include previously treated malignancies and unresolved cases of hepatitis B or C virus infection.
3. Any past or current diagnosis of a major depressive disorder with psychotic or melancholic features; bipolar affective disorders; schizophrenia of any subtype; delusional disorders of any subtype; dementias of any subtype; anorexia nervosa; or bulimia nervosa.
4. Alcohol or other substance abuse within 2 years before the onset of the chronic fatigue and at any time afterward.
5. Severe obesity as defined by a mass index [body mass index = weight in kg/(height in metres)²] equal to or greater than 45.

**CRITERIA FOR DIAGNOSIS OF DEPRESSION
- SINGLE EPISODE OR RECURRENT**

**(Based on a moderate or severe level
in ICD-10 and consistent with DSM-IV)**

1. Duration of at least two weeks.
2. At least two of the following symptoms:
 - depressed mood
 - loss of interest and enjoyment
 - increased fatiguability
3. At least three of the following symptoms:
 - reduced concentration
 - reduced self esteem and self confidence
 - ideas of guilt and unworthiness
 - bleak and pessimistic views of the future
 - ideas or acts of self-harm or suicide
 - disturbed sleep
 - diminished appetite
4. Usually considerable difficulty in continuing with social, work or domestic activities.

CRITERIA FOR 'HEALTHY' GROUP

1. No ongoing physical or mental illness.
2. Patients would be suitable if they are attending for a single, casual and non-urgent matter which is unlikely to require continuing medical care eg a short term common virus, a minor physical injury, contraceptive medication, routine checkups etc.
3. Do not include any patients with minor ailments who you consider may be hypochondriacal.

Please ring if you are unsure whether to include a person (ph 2302228).

**BASIC DEMOGRAPHIC DETAILS OF THOSE APPROACHED WITH
QUESTIONNAIRE**

(Pls complete a section for each patient included)

Name of Doctor: _____ Ph: _____

1.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

2.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

3.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

4.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

5.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

6.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

7.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

8.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

9.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

10.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

11.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

12.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

13.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

14.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

15.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

16.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

17.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

18.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

19.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

20.

Which group: CFS ☐ Depressed ☐ 'Healthy' ☐

Sex: Male ☐ female ☐ Age: _____

Marital status: married/defacto ☐ single/separated/divorced/widowed ☐

Education: Less than Yr 12 ☐ Yr 12 ☐ Diploma or degree ☐

Attachment 2

Counseling Approaches Found Useful

COUNSELLING APPROACHES FOUND HELPFUL

RECORD NO.	ILLNESS	COUNSELLING APPROACHES FOUND HELPFUL	OTHER COMMENTS
1	<u>CFS</u>	listening, monitoring, break isolation of not talking about illness, <u>not</u> advice, couple counselling	
2		grief counselling, goal setting	
3		being easier on self	
4		acknowledging physical, taking care of self, practical suggestions/help (rest place at work, hours of work, temp, financial support options), equal approach in managing illness, partner counselling/ support	
5		some psychology counselling would be helpful	"thank <u>you</u> "
7		GP - understanding, broadminded; homeopath - advice and treatment seemed to help; yoga - calming and stretching	
15		like more understanding of CFS	
17		lowering standards, gradual increase in activity. Bed rest did not help so with naturopath got back to 4 hours per day work, mothering and general duties	glad there is more research into CFS
18		talking, relaxation, knowledge, about CFS, massage	"P.S. Not sure if I have : 1. Depression; 2. Fibro Myalgic Syndrome; and/or 3. CFS"
20		possibly group counselling with others with CFS, hypnosis therapy	
21		possibly support group with others with CFS to normalise	
22		validation of an organic disease, support group	
23		setting limits oneself, not what others believe are my limits (phys + emot)	
24		understanding of limitations, reduced expectations, family counselling, depression counselling, relaxation and stress management	
38		understanding re difficulty having symptoms others can't see, getting self to take illness seriously (not faking) so will accept rest, needed to learn to relax own standards and to perceive as not coping	
39		validate the illness, physical not psychological, support and listen	
41		general family counselling	
50		accepting symptoms even though medical investigatory tests negative	
51		massage, acknowledgement that pain is real, spiritual support and challenge, stress, working through incest and violence	
54		understanding difficulty of life with CFS, pain management, self-esteem work, 1:1 counselling	

63 not as depressed person - have high motivation although suffer depression, grief of a
 64 chronic illness, non-judgemental, non-solution listening
 66 pain counselling. Counselling for CFS - "you would be desperate to try anything just
 72 to get back to normal"
 73 "practical support yes, actual counselling NO"
 "I found it was easier to deal with myself rather than rely on counselling"
 "psychologists indicated they believed problem to be medical and that I did not
 have a psychological problem"

happy to discuss further

75 recognise and acknowledge you are sick, listen, lots of support re chronic illness and
 79 to cope with frustration and depression
 81 relaxation, meditation, self hypnosis, pain management, self assertiveness, conflict
 resolution
 85 need medical knowledge, counsel self

8 Depression Rogerian, Gestalt, RET, TA, Existential therapy, self monitoring, acceptance
 26 reading material, looking after self and family first, dealing with the past
 27 PTSD - stress management course at Vietnam Vets Counselling Service, allowing to
 lower expectations
 42 panic - concentrating and focussing on talking self out of it, talking with someone
 approachable
 45 questioning own negative thoughts and feelings of unworthiness, suggestions for
 dealing with things, teaching me to be kinder and gentler on myself
 46 not directive, be accepting, caring and understanding, "one of the most helpful people
 has been my own doctor who provides 'support' through homeopathic remedies. This
 process involves counselling and talking through issues as they arise and prescribing
 the remedy which will assist at that particular time. This woman is, however,
 extremely caring and supportive and that is the most important thing."
 47 "wise woman, Homeopathy - wholist practitioner who treats you with respect,
 acknowledging the real situation you are in."
 48 "affirming - listening - validation - constructive suggestions. Homeopathy -
 gentleness, love, humour, respect . Self help groups/ doing inner child work/
 affirmations. Relaxation tapes/ positive books/ re parenting self"
 49 NLP
 59 Graded exposure to feared objects or situations, gaining rational responses to

61 situations, relaxation exercises, explanations of what is happening to me
help in seeking underlying causes, understanding aspects of my personality which
result in my being the way I am

69 “Trying to understand what the ‘big D’ is all about. The hardest time was at the start
as I did not know what was happening to me and it was not until I spoke to a GP that
he was able to put a label on it and he also told me that I would get over it. Initially I
thought I might [be] bad for the rest of my life.”

82 “Admitting to myself that I was ill and not imagining it. Learning techniques to
relax (ie yoga).”

83 relaxation methods, rehabilitation for work, goal setting

86 keeping a daily journal

89 hypnotherapy, talking, medication, self help books, positive thinking

90 psychodrama, dream analysis, inner child work, family of origin work